CAR T-cell therapy

For acute lymphoblastic leukaemia (ALL)

leukaemiacare.org.uk

Leukaemia Care

About Leukaemia Care

Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.

Helpline: Contact us for advice, support or a listening ear.

- Call our freephone helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Message us on WhatsApp: **07500 068065** (weekdays 9am to 4.30pm)
- Email **support@leukaemiacare.org.uk**

Support groups: Connect, share experiences and find comfort from other people who've been affected by ALL.

Buddy support: Chat to someone who's had a similar experience to you and understands what you're going through.

Facebook groups: Connect online with other people with ALL or their carers.

Advocacy and welfare team: Get support with the practical things in life, like money, work and your rights.

Counselling service: Access up to six sessions of counselling to help you cope with the emotional impact of ALL.

Cost of living service: Apply for a one-off grant to help with essential living costs.

Will service: Write a free, simple Will so you know what happens to your money, property and belongings when you die.

Information: Find reliable information online and in print.

To access our services or find out more:

- Scan the QR code
- Call **08088 010 444**
- Search ‘support and community’ at **leukaemiacare.org.uk**

Contents

This information is aimed at people in the UK. We do our best to make sure it is accurate and up to date but it should not replace advice from your health professional.

There is a lot of information about cancer on the internet. Some of it may not be reliable or up to date. A lot of it may not apply to you. Your doctor or nurse is your best source of information because they know you and your situation. If you want to search for information yourself, look for trustworthy organisations like the NHS or national charities. Check for a quality mark, such as the PIF tick.

This resource was funded by Autolus. In accordance with our policies, Autolus had no editorial input into the content, format, layout or design.

Introduction

There is a lot of information in this booklet. Each chapter has a summary at the beginning if you'd prefer a short overview.

This booklet is about CAR T-cell therapy for people with acute lymphoblastic leukaemia (ALL). We cover what it is and what it involves.

We'd like to thank the expert reviewers and patient contributors who helped us with this information:

- Professor John G Gribben, Barts Cancer Institute
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- Jessica Griffiths, Manchester University NHS Foundation Trust
- Luminita Keating, Addenbrooke's Hospital
- Patient reviewers George, Karen, Sophie and Tracy
- Everyone who shared their own experience so others feel less alone

This booklet includes addresses and QR codes that link to more information or support online. If you cannot access the links, please email **information@leukaemiacare.org.uk** or call **08088 010 444**.

About CAR T-cell therapy

Summary

- CAR T-cell therapy is a type of cancer treatment that uses your own blood cells to recognise and kill cancer cells.
- It's an intensive treatment that takes place at specialist centres. This may not be your usual hospital.
- You usually stay in hospital to have it and must stay near the hospital for a few weeks afterwards.
- Your doctor might recommend it if you have B-cell ALL that has not responded to treatment or has come back after treatment.
- Three different CAR T-cell therapies are available to treat ALL in the UK. They all work in a similar way. Different ones are used to treat different people.

What is CAR T-cell therapy?

CAR T-cell therapy is a type of personalised cancer treatment. It involves modifying your own blood cells so they can recognise and kill cancer cells.

CAR T-cell therapy uses blood cells called T cells.

- T cells are a type of white blood cell. They are also called T lymphocytes.
- They are part of your immune system, which helps your body fight infections.
- T cells usually recognise and destroy damaged or infected cells. This includes cancer cells.
- But cancer cells are good at disguising themselves so your T cells can't spot them.
- CAR T-cell therapy is a way of training your T cells to recognise cancer cells they could not find before.

CAR stands for chimeric antigen receptor. It's a technical name based on the way the T cells are modified.

CAR T-cell therapy is an intensive type of treatment. It can be effective at treating leukaemia that has relapsed or not responded to treatment. For some people, it can lead to long-term remission and may be curative. But it can also cause serious, and even life-threatening, side effects. You are monitored closely so these can be recognised and treated promptly.

CAR T-cell therapy is provided at specialist centres that have the necessary facilities and trained staff to deliver it safely.

Most people stay in hospital for a few weeks to have CAR T-cell therapy. This might not be your usual hospital.

After you leave hospital, you need to stay nearby for around a month after having your T cells. This is so the team can monitor you closely and manage any complications you might get.

Our **CAR T away from home service** can help with costs or accommodation if you need it. Follow the link, scan the QR code or search 'CAR T' at **leukaemiacare.org.uk**

Some centres might offer some of your CAR T-cell therapy as an outpatient. You still have to stay nearby and you must have an adult with you. You visit the hospital every day for checks.

“When Spencer had CAR T-cell therapy in London, we were deeply grateful for the generous support from Leukaemia Care. Their help enabled my husband and me to stay nearby and care for Spencer throughout his treatment. This lifted a huge burden and allowed us to focus entirely on caring for our son.”

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

Who might have CAR T-cell therapy?

CAR T-cell therapy is used to treat some people with B-cell acute lymphoblastic leukaemia (B-cell ALL). It's also used to treat some people with blood cancers called lymphoma and myeloma. This booklet is about CAR T-cell therapy for ALL.

CAR T-cell therapy can be used to treat adults and children. It is an intensive treatment, so it's not suitable for everyone.

Your haematology team might recommend it for you if you have B-cell ALL that:

- Has not responded to treatment
- Has come back after treatment

"When ALL came back a second time, I felt so lucky that CAR T had emerged. Having had a lot of chemotherapy and a stem cell transplant in the past, this gave my family and me hope for the future."

George, who had CAR T-cell therapy for ALL in 2026

Types of CAR T-cell therapy

In the UK, three different CAR T-cell therapies are approved to treat ALL. They all work in a similar way.

Brexucabtagene autoleucel (brexu-cel)

- Brand name Tecartus
- Suitable for people 26 and over
- Available to treat B-cell ALL that has not responded or has come back after treatment

Obecabtagene autoleucel (obe-cel)

- Brand name Aucatzyl
- Suitable for people 26 and over
- Available to treat B-cell ALL that has not responded or has come back after treatment

Tisagenlecleucel (tisa-cel)

- Brand name Kymriah
- Suitable for people 25 and under
- Available to treat B-cell ALL that has not responded to treatment, has come back after a stem cell transplant or has come back more than once

Before having CAR T-cell therapy

Summary

- If CAR T-cell therapy might be an option for you, your team will explain the benefits and risks. It's important to ask any questions you have to help you make an informed decision.
- You may want to ask about ways to preserve your fertility, if you have not already.
- Your team should talk to you about what support you might need during and after treatment, and how you can access this.
- You'll have tests and scans to make sure CAR T-cell therapy is suitable for you and you're well enough to have it. If you do not already have one, your team may fit a central line.
- Most people stay in hospital for a few weeks to have treatment. After you leave hospital, you must stay nearby, with an adult caregiver, for at least 28 days after having your CAR T cells.
- If you live further away, you'll need accommodation. Your hospital should be able to arrange this. Or Leukaemia Care can help.
- You'll need time off work, school or education during your treatment and recovery. Your team can tell you what to expect.

Deciding whether to have CAR T-cell therapy

If your haematology team think CAR T-cell therapy might be suitable for you, they will talk to you about it. They'll explain what the treatment involves and why they think it might be a good option for you. They will also tell you the possible risks of the treatment.

If you decide you'd like to consider the treatment, they'll refer you to a regional CAR T centre. This might be some distance away.

The team there will assess you to make sure CAR T-cell therapy is suitable for you.

The CAR T team will give you detailed information about the process. This will help you decide if it's the right choice for you. You might find it helpful to discuss it with family or friends before you make up your mind. But the decision is yours. Nobody else can, or should, make it for you.

Having CAR T-cell therapy is a big decision. Make sure you ask any questions you have. It's OK to ask a question more than once if you can't remember or don't understand the answer. Your team will be used to this. They'll be happy to explain things as many times as you need.

Things to consider

CAR T-cell therapy can be challenging. Most people stay in hospital for several weeks. Some might need to spend some time in intensive care, where staff have the training and equipment to monitor and treat some of the more serious side effects of treatment.

You need to stay in or close to the hospital for 28 days after having CAR T cells. You must have an adult with you during this time who can drive you back to hospital if necessary. This is so you can get medical help quickly if you need it.

If you do not have an adult who is able to support you, you may need to stay in hospital for these 28 days.

CAR T-cell therapy can be difficult emotionally. It is important to have strong social and emotional support.

If you need it, your team can refer you for counselling or psychological support.

It can help to talk to someone who understands what you're going through. We can help you connect with others who've been through a similar experience. We can also help you access counselling.

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email **support@leukaemiacare.org.uk**
- Visit **leukaemiacare.org.uk**

Fertility options

Scientists do not know if CAR T-cell therapy itself affects fertility. But some of the medicines used to prepare you for the treatment may affect your fertility.

If you might want children in the future and you have not already discussed your fertility, tell your doctor or nurse. They can talk to you about your options. This could include freezing eggs, sperm or embryos. This may not be possible for everyone. Your haematology team may refer you to a fertility specialist.

Pregnancy

Scientists do not know if CAR T cells are passed on to a baby during pregnancy. If they are, they could potentially harm your baby.

If you could get pregnant, you will have a pregnancy test before starting treatment. If you **are** pregnant, your team will talk to you about the risks and benefits of treatment.

CAR T-cell therapy is not recommended for pregnant women.

If you could get pregnant, you must use effective contraception during CAR T-cell treatment and for some time afterwards. Your team will tell you how long this needs to continue. It must include at least one barrier method, like a condom, diaphragm or cap.

Breastfeeding

Scientists do not know if CAR T cells pass into breastmilk. If they do, they could potentially harm your baby.

Preparing for CAR T-cell therapy

A few things will happen before CAR T-cell therapy starts.

Counselling and emotional support

Your CAR T team should talk to you about psychological support you might need during and after your treatment. Some centres may offer counselling or an appointment with a psychologist. Others might signpost you to charities or other support organisations that can help.

We offer a **counselling service** that can help you, and your family members, access up to six sessions of counselling, free of charge.
Follow the link, scan the QR code or search 'counselling' at **leukaemiacare.org.uk**

Your CAR T team may be able to recommend other support services for you and your caregiver. Or look at our list of useful organisations on **page 62**.

Tests and scans

You'll have lots of tests and scans to make sure CAR T-cell therapy is suitable for you. And that you are well enough to have it. These might be at your local hospital or at your CAR T centre.

These might include:

- Blood tests to check your blood counts, liver function and kidney function
- Blood tests to check for viral infections that could flare up
- Tests and scans to check your heart and lung function
- A pregnancy test
- Dental checks
- A lumbar puncture or brain scan, if you have ALL in your central nervous system

You might not need all these tests. Depending on your symptoms and results, you might have other tests too.

“I had to wait for a few days to find out whether I was eligible for the treatment... this was a really scary time. I am just so glad I had such a supportive team around me to help me navigate this.”

Sophie, who had CAR T-cell therapy for ALL in 2019

Your nurse will ask for a sample of your handwriting so they know what it usually looks like. Every day during your recovery, they'll ask you to write the same sentence and compare it to your usual handwriting. This helps them check for complications.

“I thought carefully about what I'd want to write twice a day for a month. I chose a Winnie the Pooh quote.”

George, who had CAR T-cell therapy for ALL in 2026

Having a central line fitted

CAR T-cell therapy involves having lots of medicines through a drip. You'll also have frequent blood tests. Your team may fit a central line to make this easier, if you don't already have one.

A central line is a long, thin plastic tube that enters the skin in your arm, chest, neck or groin. It ends in a large vein near your heart. It can be used to give treatment straight into your veins, and to take blood samples.

A central line can stay in place for weeks or months. Having one fitted means:

- You don't need a tube put into a vein every time you go for treatment
- You don't need to have a needle put into your arm when you have blood tests
- Your treatment goes into larger, sturdier veins that are less likely to leak or be damaged

You'll need to keep your central line clean and dry to reduce the risk of infection. It also needs to be flushed with sterile fluid once a week to stop it getting blocked. While you're in hospital, a nurse will do this. Once you leave hospital, your team will arrange for someone to do it for you. This might be at a hospital appointment or by a hospital community team.

Holding treatment

You might not start CAR T-cell therapy straight away. In this case, you may need treatment to keep your ALL under control until you have your T cells collected. This is called holding treatment.

If you need it, your team will tell you what holding treatment they recommend for you.

Practical things to think about

During your treatment you'll probably need to stay in hospital for a few weeks. Planning ahead as much as possible can make this easier.

If you have children, you may need to arrange for someone to look after them. You might have family or friends who can help. Your child's school may offer breakfast or after-school clubs. Or you may consider contacting your council's family information service.

Macmillan have more **information about arranging childcare**. Scan the QR code or search 'childcare' at **macmillan.org.uk**

You might need to arrange for someone to look after your home while you're away. This might include looking after pets or watering any plants you have.

Accomodation

For the first 28 days after having CAR T cells, you must stay within 1 hour's travel from your CAR T centre. You must have an adult with you at all times.

The exact distance varies depending on your treatment and your hospital's policy. Some centres might let you stay further away. It is important to follow your centre's recommendation.

If you live further away, you'll need accommodation close to the hospital. Your CAR T team should be able to help arrange this free of charge.

Our **CAR T away from home service** can help with costs or accommodation if you need it. Follow the link, scan the QR code or search 'CAR T' at **leukaemiacare.org.uk**

Arranging an adult caregiver

If you leave hospital less than 28 days after having your CAR T cells, you'll need an adult to stay with you all the time. They must be able to drive so they can take you back to hospital quickly if they need to.

They'll also help monitor your symptoms to help spot any complications early. Your CAR T team will explain what they need to do, what symptoms to record and when to seek help. They should also discuss what support is available, as it can be difficult emotionally.

You'll need to consider who might be able to do this for you. If you do not have an adult who's able to support you, you may need to stay in hospital for these 28 days.

Packing

> Ask your team about the facilities on the ward you'll be staying on, like a fridge, TV or wifi.

There are some essentials you'll need for your hospital stay. Things to keep you occupied are also a good idea, as you might spend a lot of time on your own. You may also want things to help make your stay more comfortable.

These might include:

- Loose nightwear or loose-fitting comfortable clothes.
- Socks, slippers and underwear.
- Toiletries, including a soft toothbrush, toothpaste, tissues and wipes. Your team might give you disposable, one-use toothbrushes to reduce the risk of infection.
- Your mobile phone, laptop or tablet, chargers and headphones. These let you watch films, make calls, play games or listen to audiobooks.
- Books, magazines, games or crafts. Or a yoga mat, resistance band or handheld weights if you feel well enough to be active.
- Credit or debit card, small amounts of change or cash.
- A bag for dirty laundry.
- A sleep mask and earplugs.
- A cosy blanket and your own bedding and towels, if your hospital allows this.
- Cards, photos or pictures to brighten up your room.
- Any aids you use, like glasses, hearing aids, a walking stick or dentures.
- Period products, if you need them.
- Your favourite tea, coffee, squash and snacks, if your hospital allows this.
- A hairdryer, if you usually use one.

Work or education

You'll need some time off work, school or education during your treatment and recovery. Speak to your CAR T team about what they expect for you.

You may want to talk to someone about your needs and adjustments. This could be your manager, HR, occupational health, workplace union, teacher or student union. When talking to them, you might want to:

- Explain that you're having treatment and will need time off
- Find out what support or adjustments they can offer
- Ask about sick leave, sick pay, occupational health or other policies

Our advocacy and welfare team are here if you need **advice on finances, help applying for benefits, or support with employment issues**. Scan the QR code, call **08088 010 444** or email **support@leukaemiacare.org.uk**

Your CAR T team may recommend other organisations who can support you. Or look at our list of useful contacts on **page 62**.

Having CAR T-cell therapy

Summary

CAR T-cell therapy involves a few steps:

- Collecting your T cells. This usually happens at your CAR T centre. It takes a few hours.
- Making the CAR T cells. Your cells are sent to a specialist lab for this step. It takes a few weeks.
- Keeping your ALL under control. While your CAR T cells are being made, you may need treatment to keep your leukaemia stable.
- Preparing for the CAR T cells. This involves a short course of chemotherapy. You have it about a week before your CAR T cells.
- Having the CAR T cells. This is a very quick process that only takes a few minutes.
- Monitoring for complications. Most people stay at their CAR T centre for at least 10 to 14 days. And then stay nearby for a few more weeks.

The CAR T-cell therapy process

CAR T-cell therapy involves a few steps:

- Collecting your T cells
- Making the CAR T cells
- Keeping your ALL under control
- Preparing for the CAR T cells
- Having the CAR T cells
- Monitoring for complications

“When I saw it, I couldn’t quite believe this tiny bag of cells was going to potentially save my life. I’m so glad it did.”

Sophie, who had CAR T-cell therapy for ALL in 2019

Collecting your T cells

You usually go to your CAR T centre to have your T cells collected. Unless you're already staying in hospital, you can usually go home afterwards.

Steroids and some other medicines affect the number of T cells in your blood. You'll need to stop these a few days or weeks before having your T cells collected. Your team will tell you what medicines you should stop and when to stop them. You might need other approaches to help relieve your symptoms during this time.

It usually takes 3 to 6 hours to collect your T cells, so it's a good idea to take something to do. You'll have to keep fairly still so you won't be able to walk around.

"For both procedures, Spencer had a line inserted under general anaesthetic into his groin to harvest the cells. Once the medical team confirmed that enough cells had been collected, the line was removed."

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

- You'll have blood tests first to check your blood counts, liver and kidney function, mineral levels, and test for infections.
- A doctor or nurse will measure your height and weight. This helps them work out how much blood they need to take from you.
- They put a thin plastic tube in each of your arms. If you already have a central line, they'll check if it's suitable to use this instead.
- They connect the tubes to a machine.
- The machine takes blood out of one arm. The blood passes into the machine, which filters out your T cells. The rest of your blood goes back into your other arm.
- It takes about 3 to 6 hours. A nurse checks your heart rate, temperature and blood pressure throughout.
- When it's done, the T cells are sent to a lab. Depending on which T cell therapy you are having, they might be frozen first.

The process uses an additive to stop your blood clotting. This can sometimes cause low calcium levels. Tell your team if:

- You feel numbness or tingling around your mouth or in your hands or feet
- You get muscle cramps
- You are feeling sick or being sick

They can give you calcium supplements if needed.

Making the CAR T cells

Your T cells are sent away to a lab, which might be in the UK or overseas. Here, scientists modify the cells so they can recognise and stick to proteins on the surface of your leukaemia cells.

The protein the CAR T cells stick to is called CD19. It's found on the surface of B cells and plays a role in the growth and development of leukaemia cells.

After the scientists have modified your cells, they grow them so there are enough for your treatment. Then they freeze them and send them back to your hospital.

Sometimes, the manufacturing process doesn't work as expected. It might not be possible to make the CAR T cells, or there might not be enough of them. If this happens, your haematology team will discuss your options with you.

Keeping your ALL under control

Making the CAR T cells can take a few weeks. You'll probably need treatment to keep your leukaemia cell count as low as possible while you wait. This is called bridging therapy. You might have it at your usual hospital or at your CAR T centre.

Your team will explain what bridging therapy they recommend for you. It could be:

- Chemotherapy
- A targeted medicine like imatinib
- An antibody treatment like inotuzumab ozogamicin

You might have a bone marrow test during this time too.

For **more information about ALL treatments**, scan the QR code, follow the link or search 'treatments' at **leukaemiacare.org.uk**

Preparing for the CAR T cells

After your CAR T cells have arrived back from the lab, you have a short course of chemotherapy. This reduces the number of white blood cells and immune chemicals in your bloodstream.

You might hear people call it **lymphodepleting therapy** or **conditioning therapy**.

You have conditioning therapy about a week before having your CAR T cells. Most people stay at their CAR T centre to have it. But some people might have it at their usual hospital.

Conditioning therapy:

- Makes your body less likely to react to the CAR T cells
- Helps the CAR T cells work better
- Helps the CAR T cells multiply in your bloodstream

Your CAR T team will explain what conditioning therapy they recommend, and what to expect from it. This includes information about possible side effects.

Most people have a combination of chemotherapy medicines called fludarabine and cyclophosphamide.

You have them over a few days, with a gap of at least 2 days before having your CAR T cells.

Conditioning chemotherapy can cause very low blood cell counts for a few weeks. So you'll probably have medicines to help prevent infections too.

You'll also have medicines to help prevent a complication called tumour lysis syndrome. This can happen if lots of leukaemia cells break down at once and release chemicals into your bloodstream. This can make you very unwell while your body tries to cope with changes to your body salts and levels of uric acid. As well as preventative medicines, you'll be monitored closely so you can be treated promptly if this happens.

Having the CAR T cells

The day you have your CAR T cells is sometimes called day 0. It only takes a few minutes. Some people say it feels like an anti-climax.

On the day:

A specialist nurse checks you are well enough to have the CAR T cells. They explain what will happen and ask for your consent.

The nurse gives you paracetamol and an antihistamine. This reduces the risk of having a reaction to the CAR T cells.

If you do not have a central line, they put a thin plastic tube into your arm. If you have a central line, they can use this instead.

The nurse defrosts the CAR T cells and gives them to you straight away through a drip into your arm or central line. It only takes a few minutes.

They stay with you all the time to check for any reactions to the cells.

Once you've had the cells, the nurse gives you fluids through the drip. This makes sure there are no cells left in the drip tubing.

“I got my wife to bring party hats and balloons on the day I had my cells so we had a CAR T party to recognise its significance.”

George, who had CAR T-cell therapy for ALL in 2026

If you are having obe-cel (Aucatzy), you have a second dose of CAR T cells 9 days later. The 28-day monitoring period is counted from the first dose.

Some people have a mild reaction to the preservative used to store the CAR T cells. Tell your team straight away if you:

- Feel warm or flushed
- Get a rash
- Start coughing

“Actually receiving the cells feels like a bit of an anti-climax as they’re dripped into your body in 10 to 15 mins and then it’s a waiting game.”

Tracy, who had CAR T-cell therapy for ALL in 2025

“The moment of opening the CAR T container with the nitrogen steam fizzing out is a great piece of theatre. Sadly I missed mine as there wasn’t a plug outside my door. I wanted my wife to film it!”

George, who had CAR T-cell therapy for ALL in 2026

You or your visitors might notice a smell a bit like boiled sweetcorn. This is from a preservative added to the CAR T cells so they’re not damaged by the freezing process. It’s harmless. Your body gets rid of it in your pee, sweat and breath. The smell might last for a couple of days.

Monitoring for complications

You need to be monitored for at least 28 days after having your CAR T cells. You may not need to stay in hospital for the whole of this time.

Most people stay in hospital for at least 10 to 14 days after having CAR T cells. During this time, you are monitored closely for side effects and complications (**page 38**).

You have blood tests every day to check your blood cell counts, liver and kidney function, and blood clotting.

A nurse checks your temperature, heart rate and blood pressure several times a day and at least once in the night. They also record how much fluid you drink (or have through a drip) and how much you pee. They weigh you every day.

Several times a day, the nurse asks you questions like what date it is and where you are. They also ask you to write the same sentence each time so they can check your handwriting. This is called an ICE assessment. It helps them spot any nervous system complications early (**page 43**).

You might have some heart tracings (ECGs).

Tell your doctor or nurse straight away if you feel unwell.

They can check for complications of CAR T-cell therapy and start treatment quickly if you need it.

Once your blood counts are high enough and you're well enough, you can go home. If you live more than 1 hour's travel from the CAR T centre, you might move to accommodation nearby instead.

You must stay close to your CAR T centre for at least 28 days after having your CAR T cells. During this time, you must have an adult caregiver with you.

"Spencer had his first CAR T-cell therapy at our local hospital, which meant that after treatment we could return home, where he stayed in isolation but was still able to enjoy his home comforts."

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

When you first leave hospital, you'll have frequent check-ups and blood tests. You and your caregiver also need to monitor your health closely during this time. This includes noting any symptoms or side effects, and taking your temperature twice a day.

Your doctor or nurse will talk to you and your caregiver and give you written information explaining:

- Symptoms to look out for and what to do if you get them
- When and how to contact your CAR T team
- How to get urgent medical help

They may give you and your caregiver forms to record your temperature and how much you're drinking and peeing. And an ICE assessment form with questions to check for nervous system problems.

They should also give you an alert card to show any health professionals who look after you. This explains that you've had CAR T-cell therapy and the complications you might get.

"Spencer was closely monitored by the medical team and continues to be followed up regularly."

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

Side effects and complications

Summary

- CAR T-cell therapy can have several side effects or complications. You might get some of them but not others.
- Some complications can be serious. Your CAR T team will monitor you closely for these.
- The most common serious complications are:
  - Low blood counts
  - Cytokine release syndrome
  - Nervous system problems
- Your team will explain what symptoms to look out for.
- **Contact your team straight away if you have any symptoms or feel unwell.**
- CAR T-cell therapy can also lead to other health problems months or years later. Your team will tell you what to be aware of.

About side effects and complications

CAR T-cell therapy can cause many side effects or complications. You might get some of these but not others. Some are mild or moderate. But some can be serious or even life-threatening.

> Side effects and complications are usually at their worst within 1 to 2 weeks of having the CAR T cells. After that, they tend to get better gradually. Many people start to feel better within around 3 months but it can take 6 months or more.

Side effects or complications can be from the conditioning therapy or from the CAR T cells. You might also be dealing with side effects from previous treatments.

The most common serious complications are:

- Low blood counts
- Cytokine release syndrome
- Nervous system problems

“Spencer experienced mild cytokine release syndrome and was neutropenic. Overall, we found CAR T to be a gentler treatment than a stem cell transplant.”

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

Low blood counts

The chemotherapy you have to prepare for the CAR T cells causes very low blood counts. You might hear your team call this ‘cytopenia’.

If your red blood cell count is low, you may feel tired and breathless. You might get a fast or uneven heart rate. You’ll have transfusions to top up your red blood cells if needed.

If your platelet count is low, you might bleed or bruise easily. You’ll have transfusions to top up your platelets if you need them.

If your white blood cell count is low, you have a high risk of getting an infection, which could be very serious. You cannot have a transfusion to top up your white blood cells, because they don’t survive long outside the body. But there are things you, your CAR T team and your visitors can do to keep your risk of getting an infection as low as possible.

Tell your CAR T team straight away if you feel unwell, especially if you have chills or feel feverish.

Reducing your risk of infection when you're in hospital

- Your CAR T team will monitor you for signs of infection and treat you promptly if you get one.
- They'll keep your central line clean, if you have one.
- They might prescribe antiviral, antibiotic or antifungal medicines.
- You'll probably stay in a room on your own. This should be cleaned every day.
- Try to wash yourself and brush your teeth regularly, even if your mouth is sore. Use a soft toothbrush and alcohol-free mouthwash. Your team might provide this for you.
- Anyone entering your room should wash their hands thoroughly.
- They might need to wear a mask, apron and gloves if your white blood cell count is very low.
- Anyone preparing food for you should follow standard food safety guidance.
- Visitors should stay away if they're unwell. Or if they've been in contact with someone who's unwell.

Cytokine release syndrome

Cytokine release syndrome (CRS) happens when activated CAR T cells release chemicals called cytokines. These then activate other immune cells in your body. This can trigger an inflammatory reaction.

Up to 9 in 10 people who have CAR T-cell therapy get CRS. More than 1 in 10 do not. Many cases are mild or moderate. But it can be serious if it's not treated promptly.

CRS usually happens within 14 days but it can develop up to a month after having CAR T cells. Your CAR T team monitor you closely for signs and symptoms. These include:


Fever


Flu-like symptoms


Fatigue or lack of energy


Low blood pressure

Tell your CAR T team immediately if you get any of these symptoms.

If you get CRS, your team can give you fluids, and medicines to lower your temperature. Some people might need an immune-suppressing medicine called tocilizumab, or sometimes steroids.

Nervous system problems

CAR T-cell therapy can cause problems with your nervous system. This is called immune effector-cell associated neurotoxicity syndrome (ICANS). It happens when inflammatory chemicals from immune cells leak into your nervous system.

Up to 6 in 10 people who have CAR T-cell therapy get ICANS. More than 4 in 10 people do not get it. It usually happens within 3 to 5 days of having your CAR T cells. But it can happen up to 4 weeks later.

Your CAR T team monitor you closely for signs and symptoms of ICANS. These include:


Headache


Tremor


Feeling confused or agitated


Changes to your handwriting


Difficulty speaking or finding words

In serious cases, it can cause drowsiness or fits (seizures).

Tell your CAR T team immediately if you get any of these symptoms.

Your team record your signs and symptoms using an ‘ICE assessment’. This helps them spot ICANS early and check how serious it is.

ICANS can be treated with steroids. Some people might need anti-epileptic medicines. People with severe ICANS might be transferred to intensive care, where staff have the skills and equipment to manage it.

ICANS can be very serious. But most people who get it recover well with no long-term effects.

Other common side effects

We list some other common side effects of conditioning therapy on the next page.

This is not a complete list of side effects you might get. Your CAR T team will give you information about your exact treatment, including possible side effects.

Fatigue. Many people feel completely exhausted in the weeks after having their CAR T cells. This often starts to improve after around a month.

Diarrhoea, feeling sick or being sick (vomiting). Your team can prescribe medicine to help. Anti-sickness medicine works better the sooner you have it. So tell your team straight away if you are feeling sick.

Bladder problems. You might pee more often than usual, or it might sting when you pee. You might get blood in your pee. Your team can give you medicine and fluids to help. This usually gets better after a few days.

Hair loss. This can be distressing, but it's usually temporary. If you choose to, you can cover your hair loss with hats, headscarves, wraps, turbans or wigs. When your hair grows back, it might be a different colour or texture than before.

Sore mouth or mouth ulcers. These can be very painful, and it might be hard to eat. You might need pain relief. Your team might prescribe mouthwashes or gels to help.

Tingling or pins-and-needles in your hands or feet.

Changes in your liver or kidney function. If this happens, your team might adjust your treatment dose.

Possible longer-term complications

CAR T-cell therapy can be an effective treatment for ALL that has relapsed or not responded to other options. But it can lead to other health problems months or years later. You'll have follow-up appointments to check for these.

Infections

Your immune system can be low for a long time after CAR T-cell therapy. This can be due to low B cells, low antibody levels, low levels of other white blood cells, or a side effect of steroid treatment.

When your immune system is low, you're at high risk of getting infections, which can be serious.

You, your CAR T centre and your local hospital should work together to help prevent and treat infections.

You should:

- Take precautions to reduce your risk of getting infections (**page 54**)
- Report any signs or symptoms of infection immediately (**page 53**)
- Have any vaccinations your team recommend (**page 57**)

Your team should:

- Tell you what to do if you think you have an infection
- Monitor your blood counts and antibody levels

If you need it, your team might prescribe:

- Medicines to prevent or treat infections
- Growth factors to boost your white blood cell counts
- Immunoglobulin replacement therapy (IVIG) to top up your antibody levels

Contact your team immediately if you have any signs of infection.

Low B cell counts and antibody levels

Most people who have CAR T-cell therapy have very low levels of healthy B cells, or sometimes no B cells at all, for at least 6 months after treatment. For some people it can last much longer. You might hear your team call this B-cell aplasia.

B cells usually make antibodies, which help your body fight infections. If you have low B cells, you have a higher risk of getting infections.

- You will have blood tests to monitor your B cell counts. You may need to have these for the rest of your life.
- You will also have blood tests to measure your antibody levels.
- If your antibody levels are low and you get repeated or long-lasting infections, you might need immunoglobulin replacement therapy (IVIG). This tops up your antibody levels. You have it through a drip or as an injection under your skin.

“I have to go to hospital once a month for IVIG, which is a tiny factor in the grand scheme of everything I have already been through!”

Sophie, who had CAR T-cell therapy for ALL in 2019

Why does CAR T-cell therapy cause low B cell levels?

CAR T-cell therapy for ALL works by sticking to a protein called CD19 on the surface of cells. This is how the CAR T cells recognise leukaemia cells. But healthy B cells also have CD19 on their surface. This means CAR T cells also destroy healthy B cells.

Low levels of other white blood cells

CAR T-cell therapy can cause low levels of white blood cells called neutrophils. This is called neutropenia.

After CAR T-cell therapy, neutrophil counts typically start to improve but then have a second drop.

- When your neutrophil count is low, you will need to take precautions to reduce your risk of infection (**page 54**).
- You might need growth factor treatment to help boost your white blood cell counts. You have it through a drip or as an injection under your skin. You might hear your team call it GCSF.

Other long-term effects

Some people get longer-term effects after CAR T-cell therapy. These may include:

- Leukaemia coming back again
- Exhaustion or fatigue
- Heart problems, especially if you had severe cytokine release syndrome
- Nerve problems
- Lung problems
- Getting a different cancer

Your CAR T team will tell you what symptoms to look out for and what to do if you notice them.

To reduce the risk of problems and spot them early if they do happen, it's important to:

- Attend all your follow-up appointments
- Go to any screening tests you're invited to

Summary

- You can leave hospital once your blood counts are at a safe level and you're feeling well enough.
- You must stay close to your treatment centre for 28 days after having your CAR T cells.
- Contact your CAR T team immediately if you have any signs of infection, cytokine release syndrome or nervous system problems. They will tell you what signs to look out for.
- After you go home, you'll have regular follow-up appointments and blood tests. These might be shared between your local hospital and your CAR T centre.
- Try not to expect too much of yourself at first. Build up your activity levels gradually and rest when you need to.
- It's important to take simple steps to reduce your risk of infection.

Leaving hospital

You can leave hospital once your blood counts are at a safe level and you're feeling well enough. If this is less than 28 days after having your CAR T cells, you must stay close to your CAR T centre.

"Once home, keeping Spencer isolated and protected from germs was our priority. He was neutropenic for 4 months, and developed pneumonia. He had further treatments and has fully recovered from the infection."

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

It's normal to feel anxious when you leave hospital, but your CAR T team are still there to support you. They will give you information about what to look out for, and what to do if you have any concerns.

They should also give you a card to show any health professionals who look after you. This explains that you've had CAR T-cell therapy and outlines the complications you might get.

You should not drive, use tools or machines, or take part in activities where you need to be alert, for at least 8 weeks after having your CAR T cells. This is because of the risk of nervous system complications, which may affect your ability to concentrate or make decisions.

Contact your CAR T team immediately if you have any signs of infection, cytokine release syndrome or nervous system problems.

Symptoms to look out for include:

- A high temperature (37.5°C to 38°C or higher)
- Flu-like symptoms
- Fatigue or lack of energy
- Headache
- Tremor
- Changes in your heart rate
- Feeling confused or agitated
- Changes to your handwriting
- Difficulty speaking or finding words
- Sore throat, sneezing, blocked or runny nose, earache
- Coughing or shortness of breath
- Burning or stinging when you pee, or peeing more often than usual
- Sickness or diarrhoea
- Pain, redness or swelling around your central line

It can feel strange adjusting to being out of hospital. You'll have lots of medicines to take. You may still need blood transfusions too, so you might keep your central line for a while.

Reducing your risk of infection once you've left hospital

You still have a higher risk of infection once you've left hospital. You can help keep it as low as possible by:

- Checking your temperature twice a day
- Showering every day if you can
- Washing your hands often
- Brushing your teeth regularly
- Making sure your accommodation is kept clean
- Making sure your food is prepared and stored safely
- Staying away from people who are unwell
- Avoiding crowded places
- Wearing gloves for gardening or cleaning up after pets (or asking someone else to do it for you)

You'll be monitored closely when you first leave hospital. You'll have frequent check-ups. And it's not unusual to need to go back to hospital to deal with a complication or side effects.

Recovery takes time, and you'll probably feel very tired. You might find it harder than usual to concentrate or remember things. You might struggle to sleep well, and your appetite might take a while to come back. Many people start to feel better after a few months. For some it might be sooner than this. But for others it might take longer. Everyone's recovery is different.

Try not to expect too much of yourself at first. Build up your activity levels slowly and rest when you need to.

Many people find finishing treatment to be an unsettling time. You may not feel how you expected to. We have **information on coping with your feelings when you finish treatment**. Scan the QR code, follow the link or search for 'emotions' at **leukaemiacare.org.uk**

"Within 3 months of having my cells back, I was back at university. CAR T therapy gave me my life back."

Sophie, who had CAR T-cell therapy for ALL in 2019

Follow-up

“ Spencer is doing well. He’s spending time with his friends and hopes to return to school in the near future. As a family, we are looking forward to holidays, making memories, and watching Spencer and his brother enjoy their childhood. ”

Karen, mum of Spencer who had CAR T-cell therapy for ALL in 2024 and 2025

After CAR T-cell therapy, you’ll have regular follow-up appointments and blood tests. Sometimes you might have scans or other tests. These check your recovery, look for signs of any complications and monitor your ALL.

You’ll have a bone marrow test around 28 days after having your CAR T cells. This goes to the lab to check if there are any leukaemia cells left in your body. The test is very sensitive and can measure very low levels. If no leukaemia cells can be detected, it is called MRD negative.

You may have another bone marrow test 3 months after having your CAR T cells.

Your appointments might be shared between your CAR T team and your usual hospital. They get less frequent over time.

- For the first year, you have an appointment at least every 1 to 3 months
- Then every 6 months until 2 years after having your CAR T cells
- Then once a year

You'll be followed up for at least 15 years. These appointments might be by telephone so you do not need to travel to your CAR T centre.

Vaccinations after CAR T-cell therapy

After CAR T-cell therapy, you might not respond as well to vaccines as other people. But they still offer you some protection against infection.

- You can have flu or covid vaccines from 3 months after CAR T-cell therapy. Some centres wait longer than this.
- You can have other non-live vaccines from 6 months after CAR T-cell therapy, as long as you have not had immunoglobulin replacement therapy in the past 2 months.
- You should not have live vaccines for at least 1 year after CAR T-cell therapy, or until your immune system has recovered.

If ALL comes back after CAR T-cell therapy

ALL can come back after CAR T-cell therapy. This happens in 3 to 6 in every 10 people. It does not happen in 4 to 7 in every 10 people. It might happen if the leukaemia cells stop making the CD19 protein. Or if the CAR T cells stop working.

If your team think you're **at higher risk** of ALL coming back, they might suggest further treatment to help prevent it. This could be a stem cell transplant, chemotherapy or targeted medicine.

If ALL **comes back** after CAR T-cell therapy, it can be difficult to treat. Your team will talk through your options. These depend on what treatment you've already had and how you responded. Your team might suggest a stem cell transplant or further CAR T cells. Or they might recommend treatment to relieve your symptoms and improve your quality of life.

It is distressing if ALL comes back. We are here for you if you need support.

- Call our freephone helpline on **08088 010 444**
- Message us through WhatsApp on **07500 068065**
- Email **support@leukaemiacare.org.uk**

Words you might see or hear

Acute lymphoblastic leukaemia (ALL): a fast-growing type of blood cancer that affects blood cells called lymphoblasts.

Antibody: an immune system protein that helps fight infections by sticking to targets on the surface of cells that don't belong in your body.

B cell or B lymphocyte: a type of white blood cell that makes antibodies.

B-cell aplasia: having extremely low B cell levels or no B cells at all.

Bone marrow test: a test to take a sample of the spongy tissue from the centre of a bone, usually your pelvis.

Bridging therapy: treatment to keep your leukaemia under control while your CAR T cells are being made.

CAR T cells: your own T cells that have been changed in a lab to help them recognise and kill leukaemia cells.

CAR T-cell therapy: a treatment that involves modifying your own immune cells in a lab so they can recognise and kill cancer cells.

CD19: the protein on the surface of leukaemia cells that CAR T cells stick to.

Central line: a long, thin plastic tube used to give you medicines into your veins or take blood. It enters the skin in your arm, chest, neck or groin and ends in a large vein near your heart.

Conditioning therapy: a short course of chemotherapy to get your body ready to have your CAR T cells.

Cytokine release syndrome (CRS): a complication that can happen when activated CAR T cells release chemicals called cytokines that trigger an inflammatory reaction.

Cytopenia: low levels of red blood cells, white blood cells or platelets.

General anaesthetic: a medicine to send you to sleep so you don't feel any pain during medical procedures.

Growth factor: a type of medicine that boosts your blood cell counts.

Haematology: the branch of medicine that deals with diseases of the blood and bone marrow.

Holding treatment: treatment to keep your ALL under control before you have your T cells collected.

ICE assessment: a series of questions and a handwriting test to check for signs of nervous system problems (ICANS).

Immune effector-cell associated neurotoxicity syndrome (ICANS): a complication of CAR T-cell therapy that can happen when inflammatory chemicals from immune cells leak into your nervous system.

Immune system: the cells and systems in your body that protect you from infection.

Lumbar puncture: a test to collect a sample of the fluid that surrounds your brain and spinal cord through a needle in your back.

Lymphocyte: a type of white blood cell that helps fight infections.

Lymphodepleting therapy: chemotherapy to reduce your number of white blood cells.

Lymphoma: a type of cancer that affects blood cells called lymphocytes in your lymphatic system.

MRD negative: when sensitive tests cannot detect any leukaemia cells in your body.

Myeloma: a type of cancer that develops from white blood cells in your bone marrow called plasma cells.

Neutropenia: a low level of white blood cells called neutrophils.

Neutrophils: white blood cells that help you fight inflammation and infection.

Stem cell transplant: treatment that replaces damaged or abnormal blood-forming cells in your bone marrow with healthy ones.

Steroids: medicines that reduce inflammation and have anti-cancer effects.

Supportive care: treatment to prevent or relieve symptoms or side effects.

T cell or T lymphocyte: a type of white blood cell that recognises and destroys damaged or infected cells.

Transfusion: having blood or blood products through a drip into a vein.

Tumour lysis syndrome: a serious side effect of some cancer treatments. It happens if a large number of cancer cells break down quickly and release chemicals into your bloodstream.

Useful contacts

Having CAR T-cell therapy can be challenging. Here are some organisations you might find helpful.

Leukaemia Care

- Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- WhatsApp: **07500 068065** (weekdays 9am to 4.30pm)
- **leukaemiacare.org.uk**
- **support@leukaemiacare.org.uk**

Anthony Nolan

- Provide free information, emotional and financial support for people having a stem cell transplant.
- **0303 303 0303**
- **anthonynolan.org**

Blood Cancer UK

- Provide free information and support for people affected by blood cancer.
- **0808 2080 888**
- **bloodcancer.org.uk**

Macmillan

- Provide free, practical, medical and financial support for people facing cancer.
- **0808 8080 000**
- **macmillan.org.uk**

Maggie's

- Offer free practical, emotional and social support to people with cancer and their loved ones.
- **0300 1231 801**
- **maggies.org**

How you can help us

We've built an active community centred around emotional care, practical guidance, and raising awareness. We help people spot the signs, get diagnosed earlier, and feel supported through it all.

We can't do this alone. Whether you can give your money, effort, time or kindness, it matters. Your generosity means more people feel seen, understood, and less alone.

On the next few pages are some of the ways you can help.

For more information:

- Scan the QR code or visit **leukaemiacare.org.uk**
- Call **08088 010 444**
- Write to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**
- Email the addresses listed on the following pages

Tell us what you think

Follow the link or scan the QR code to complete **a short survey** about how we can improve our information. You can also contact us for a list of sources we used.

- Email **information@leukaemiacare.org.uk**

Share your story

Real stories shape our work. Sharing your story can help others in a similar situation. It can also help people understand ALL and CAR T-cell therapy better.

- Email **communications@leukaemiacare.org.uk**

Volunteer with us

Our volunteers are at the heart of everything we do. Whether you can give a few minutes online or commit to a regular role, there are many ways you can get involved.

- Email **volunteering@leukaemiacare.org.uk**

Fundraise for us

Every fundraising activity or event, big or small, helps support people affected by leukaemia, MDS and MPN.

- Fancy the chance to win £25,000? Join our weekly lottery from as little as £1 a week.
- Ask your society, group or sports club about their charity of the year partner.
- Find out if your employer makes charitable grants or donations to good causes.
- Organise your own event. You could host a quiz night or bake sale with friends, at work or school.
- Prefer to get outdoors? Take on one of our challenges of varying levels. Walk, run – or, for the more adventurous, a skydive?

Contact our fundraising team:

- Email **fundraising@leukaemiacare.org.uk**

Donate to us

Whether you can give a little or a lot, your donation means faster diagnosis, all-rounded care, and better days ahead. There are so many ways you can give. Find one that fits you!

By bank transfer

- Account name: **Leukaemia Care**
- Sort code: **20-98-61**
- Account number: **80823805**

By cheque

- Please make your cheque payable to **Leukaemia Care**
- Post it to **Leukaemia Care, One Birch Court, Blackpole East, Worcester, WR3 8SG**

Online

- Visit **leukaemiacare.org.uk**

By phone

- Call **08088 010 444** to donate by debit or credit card

By text

- Text **LEUKCARE** to **70490** to donate £5

Every day, 28 people in the UK find out they have leukaemia. In that moment, and every moment after, we're here.

At Leukaemia Care, we support anyone affected by leukaemia because leukaemia can affect anyone. Whether you're living with it, loving someone through it, or coping with the impact of it, you're not alone.

Want to talk?

- Call our freephone Helpline: **08088 010 444** (weekdays 9am to 4.30pm)
- Message us on WhatsApp: **07500 068065** (weekdays 9am to 4.30pm)
- Visit **leukaemiacare.org.uk**
- Email **support@leukaemiacare.org.uk**

Leukaemia Care, One Birch Court,
Blackpole East, Worcester, WR3 8SG

Trusted Information Creator
Patient Information Forum

Leukaemia Care

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