

CAR-T cell therapy for lymphoma

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My lymphoma type, stage and date of diagnosis:

Key contact

Name: _____

Role: _____

Contact details: _____

Job title/role	Name and contact details
Consultant haematologist/ oncologist	
Clinical nurse specialist (CNS) or key worker	
Emergency hospital contact	
GP	

About this book

Some people with lymphoma are offered CAR-T cell therapy as part of their treatment. This book explains what CAR-T cell therapy is, the stages involved in having it, and the possible side effects.

There is a lot of ongoing research focusing on CAR-T cell therapy. This means that the exact details of who is eligible for treatment, which products are available, and how it is managed, might change with time. The details in this book were correct at the time of print and will be kept under review.

For the latest information, visit lymphoma-action.org.uk/CARTcells

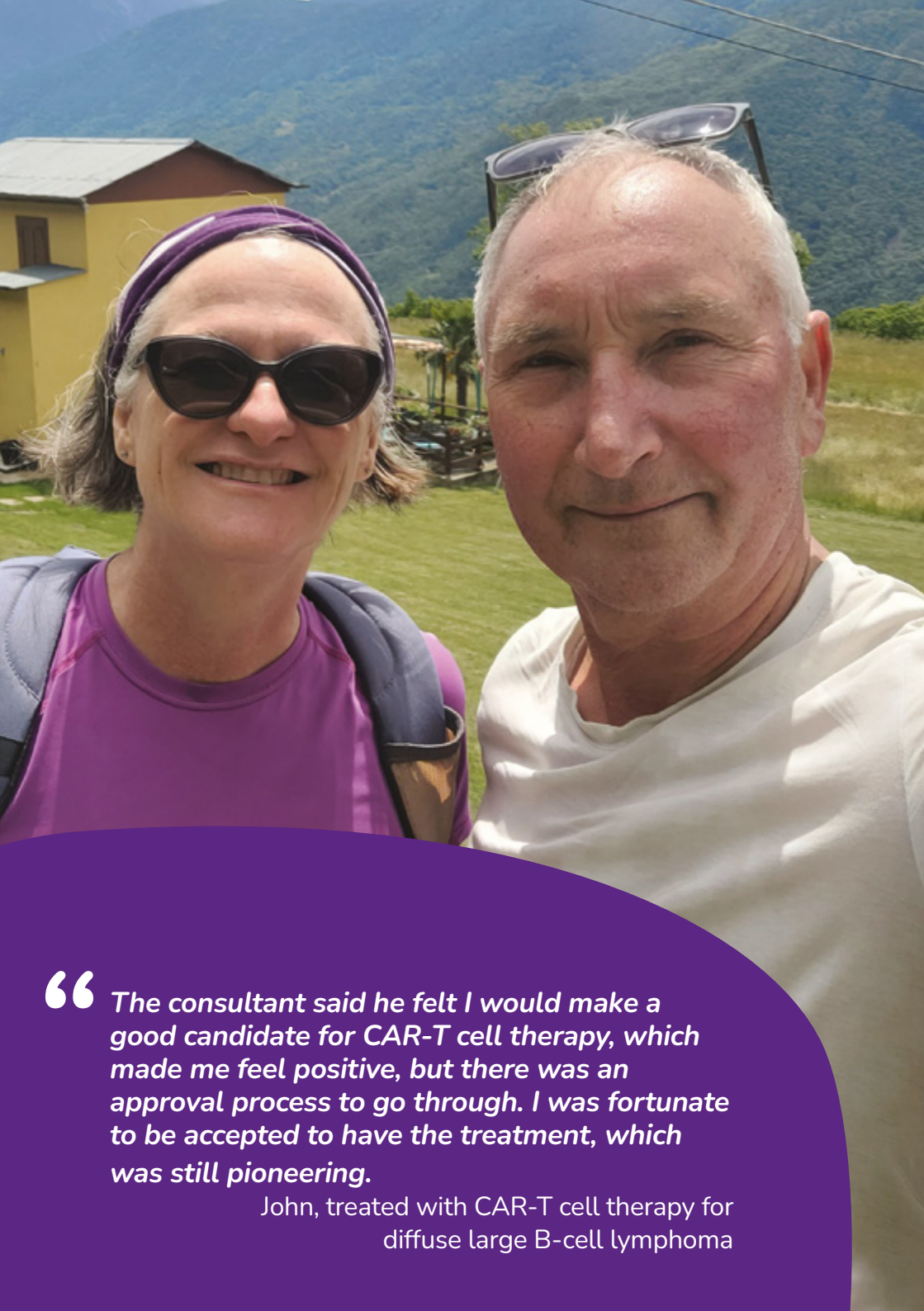
Words in **bold blue** are explained in the glossary on pages 48 to 51.

You can find our full range of resources on our website.

If you can't find the information you're looking for, or in the format you would like, please contact us (see page 52).

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What is CAR-T cell therapy?

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“ *The consultant said he felt I would make a good candidate for CAR-T cell therapy, which made me feel positive, but there was an approval process to go through. I was fortunate to be accepted to have the treatment, which was still pioneering.*

John, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

What is CAR-T cell therapy?

CAR stands for 'chimeric antigen receptor'.

CAR-T cell therapy is a specialist treatment that can be used to treat some types of lymphoma. It is a type of **immunotherapy**. This means that it uses your own immune system to fight lymphoma.

CAR-T cell therapy uses your **T cells**. T cells, or T **lymphocytes**, are a type of white blood cell. As well as killing germs, T cells can recognise and kill any of your own cells that have become abnormal (such as cancer cells). However, cancer cells are good at tricking your T cells, either by looking very similar to healthy cells or by sending signals that tell your T cells not to attack them.

With CAR-T cell therapy, some of your own T cells are genetically modified (changed) in a laboratory so they can recognise and stick to a particular protein on the surface of your **lymphoma** cells. These changed T cells are known as 'CAR-T cells'. When they stick to the lymphoma cells in your body, the CAR-T cells are activated and kill the lymphoma cells.



Find more information on our website at lymphoma-action.org.uk/CARTcells

Who might have CAR-T cell therapy?

CAR-T cell therapy can be used to treat some types of lymphoma.

Currently it is available to treat specific types of lymphoma that have come back (**relapsed**) or have not responded to treatment (**refractory**). You **might** be eligible for CAR-T cell therapy if you have:

- relapsed or refractory diffuse large B-cell lymphoma (DLBCL)
- relapsed or refractory primary mediastinal large B-cell lymphoma (PMBL)
- relapsed or refractory mantle cell lymphoma after at least two previous courses of treatment (to be eligible for CAR-T cell therapy, your previous treatment must have included a type of targeted drug called a BTK-inhibitor, such as ibrutinib)
- some other types of relapsed or refractory high-grade B-cell lymphoma that have returned within 12 months of treatment
- relapsed or refractory follicular lymphoma grade 3B.

This list is likely to change with time, possibly increasing the eligibility for CAR-T cell therapy. Clinical trials are currently testing its use to treat previously untreated lymphoma and for other types of lymphoma. If you are interested in taking part in a clinical trial, speak to your medical team to see if it is an option for you.



Find out more about clinical trials, including our database of current lymphoma trials in the UK, at lymphoma-action.org.uk/Trials

CAR-T cell therapy can be an effective treatment option for some people. However, it is a very intensive type of treatment that can have serious, and occasionally life-threatening, side effects. You have to be fit enough to tolerate the treatment. Your doctor will discuss this with you, as well as any alternative treatment options.

If your doctor thinks you might benefit from CAR-T cell therapy, they discuss your situation with a national panel of clinical experts and patient advocates. The panel considers your general health or 'performance status', as well as the results of any tests and scans to help them decide if CAR-T cell therapy is suitable for you.

You will have blood tests to find out how well your liver and kidneys are working and to check if you have any viruses that might flare up during the treatment. You might also have scans and other tests to check how well your heart and lungs are working. You might need a biopsy.



Find out more about tests and scans at lymphoma-action.org.uk/Tests

“ *In an hour-long appointment CAR-T was explained to me in detail, although it was difficult to take it all in. I am so grateful that my friend was there to summarise it for me, and that summary is something I have looked back on many times.*



I had lots of tests to assess my health including blood tests, lung function test, echocardiogram and scans. I knew there was no guarantee I would be put forward, but I was excited and nervous about the prospect of being given this cutting-edge treatment.

After the tests I had to wait to hear if I was eligible, although I didn't think they would take someone my age and at the time I was very poorly. While waiting I was living and breathing CAR-T and was thrilled when I got a call to say I would receive it.

Fiona, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

Types of CAR-T cell therapy

The exact CAR-T cell therapy you have depends on the type of lymphoma you have. The CAR-T cell therapies currently approved in the UK are called:

- axicabtagene ciloleucel (also known as axi-cel or Yescarta®)
- brexucabtagene autoleucel (also known as KTE-X19 or Tecartus®)
- lisocabtagene maraleucel (also known as lisco-cel or Breyanzi®).

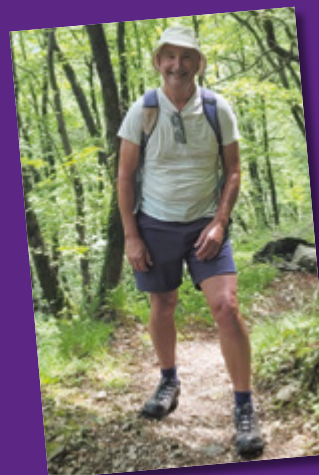
They work in very similar ways – the information given in this book is true for all available types of CAR-T cell therapy.

Additional CAR-T cell therapies are being tested in clinical trials. This list might change over time if additional types are approved for use.

Where can you have CAR-T cell therapy?

You can only have this treatment at a registered CAR-T cell therapy centre with the facilities and staff to administer it safely. If you are eligible for CAR-T cell therapy, you might have to travel some distance to have it. Your doctor can tell you more about where you will be treated.

“ Everything was explained to me really clearly, both by the consultant and also by the specialist nurse practitioner. I questioned whether I wanted to go through this. Like others, I began this process being rather in awe of the doctors, but developed a really good relationship with them and importantly trusted them. I also trusted in the science and decided to embrace it fully.



John, treated with CAR-T cell therapy for diffuse large B-cell lymphoma



Having CAR-T cell therapy

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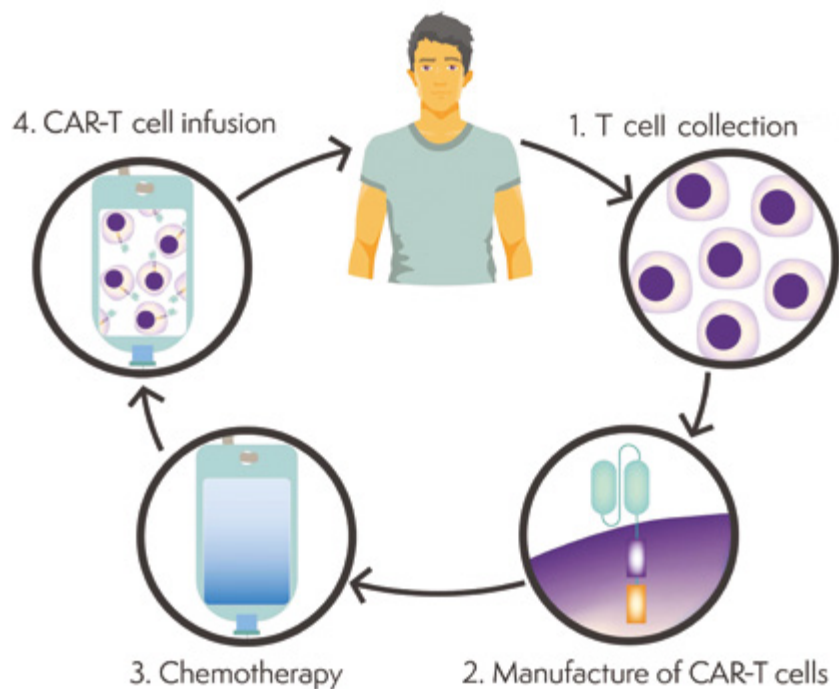
“ My T cells were collected and sent to a lab in America where they were genetically modified and grown to make enough to treat the lymphoma. This took around 5 weeks. Before they came back I had radiotherapy and 2 days of conditioning chemotherapy. The infusion of my manufactured T cells was very much like having a blood transfusion.

Matthew, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

The CAR-T cell therapy process

CAR-T cell therapy involves a number of steps:

1. Collecting your T cells
2. Making the CAR-T cells
3. Chemotherapy
4. Having CAR-T cells



The CAR-T cell treatment process

Stage 1: Collecting your T cells

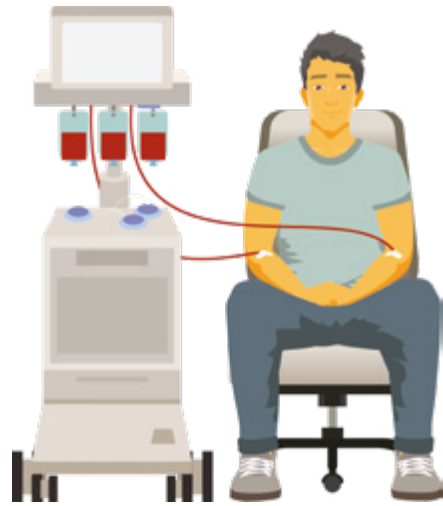
The first step is to collect your **T cells**. This process is called 'apheresis'. You have it done as an outpatient and you can go home afterwards, unless you are already staying in hospital.

Depending on what medicines you are having, you might need to stop taking them a few days before your T cells are collected, to give the drugs time to leave your system.

Often **chemotherapy** and steroids need to be avoided for a week or two before apheresis, depending on which CAR-T product you are to have.

When you are ready to have your T cells collected, a doctor or nurse puts thin, flexible, plastic tubes into a vein in each of your arms. If your veins are not suitable, a central line might need to be fitted. They connect these tubes to a cell separator machine. Your blood is taken from a tube in one arm and passes through the machine. The machine collects your T cells and returns the rest of your blood into your other arm. This process takes a few hours. You have to keep your arm still during this process and cannot move around much.

Ask your medical team if a friend or family member can stay with you to keep you company, or whether you can listen to music or a podcast.



Collecting T cells (apheresis)

Sometimes, it isn't possible to collect enough T cells for CAR-T cell therapy. If this happens, your doctor will discuss your options with you, such as trying again or alternative treatments.

Stage 2: Making CAR-T cells

CAR-T cell treatments have to be made individually for each person. Your T cells are sent away to a lab for this. In the lab, your T cells are genetically modified (changed) to recognise a protein on your lymphoma cells. They are then grown until there are enough of them to treat your lymphoma, and frozen.

Making and growing the CAR-T cells can take several weeks. During this time, you might need **chemotherapy** or **radiotherapy** to keep your lymphoma under control. This is called 'bridging therapy'.

Sometimes, the lab isn't able to successfully make the CAR-T cells. If this happens, your doctor will discuss your options with you, such as a second collection or alternative treatments.

Stage 3: Chemotherapy

Once your CAR-T cells are ready, the lab sends them back to the hospital where you're being treated. The cells are frozen and can be stored for several months.

When they arrive, your doctor checks that you are still well enough to have them. If you are not well enough to have the CAR-T cells, your medical team might need to delay your treatment or discuss other treatment options with you.

If you are still well enough, the next step is to have chemotherapy to reduce the number of white blood cells in your body. This prepares your body for the CAR-T cells so they can multiply more efficiently and work more effectively. It is called 'lymphodepleting chemotherapy' or 'conditioning chemotherapy'.

The most common type of chemotherapy used is a combination of fludarabine and cyclophosphamide, but other chemotherapy drugs are occasionally used. You usually have it through a drip into a vein, or through a central line if you have one. You might have it as an inpatient, or as an outpatient over 3 days, usually followed by a rest period of at least 24 hours.

Find out more about chemotherapy at lymphoma-action.org.uk/Chemotherapy



Stage 4: Having CAR-T cells

Once you've finished your lymphodepleting chemotherapy, you are ready to have your CAR-T cells. You have pre-medication first to help reduce any reactions. This is usually paracetamol and antihistamines (anti-allergy medicines).

The CAR-T cells will arrive frozen and will need to be thawed at room temperature or in a water bath before use.

You are given the CAR-T cells through a drip into a vein, or through a central line if you have one. It usually takes around 10 to 20 minutes. You are monitored carefully in hospital during and after the treatment.



Having CAR-T cells

“ There were quite a few medical professionals in the room as the cells were infused, which was very much like having a blood transfusion. Once the process had been completed, the medical staff left. In truth it was a bit of an anticlimax.



Matthew, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

Follow-up

Most people stay in hospital for at least 10 days after having their CAR-T cells. For many people it can be longer, depending on how well you tolerate the treatment and any complications you experience.

During this time, you will be closely monitored by your medical team. They will regularly record measurements such as your temperature, heart rate, blood pressure and weight. You will have blood tests to check **blood counts** and to test for any infections.

They will also carry out neurological assessments and observations (testing your brain function). This will include asking you various questions every day, following simple commands and assessing your handwriting.

“ Each day, I answered questions that seemed silly at first, but I noticed a change in my ability to answer them over time. I also wrote a set sentence daily, and my handwriting became unrecognizably poor in the middle.



Fiona, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

Contact your medical team if you experience:

- any signs of infection (see page 33)
- confusion
- difficulty with talking, writing or memory
- headaches or dizziness
- drowsiness.

After you leave hospital, you need to stay close by (usually within an hour's travel) for at least 4 weeks from the date of CAR-T cell **infusion**. This is because any side effects are most likely to develop in the first 30 days. Staying close to the hospital makes it easy for you to access treatment quickly if you develop any side effects. You will also be seen frequently in the clinic during this time. If you live more than an hour away, you might need to arrange accommodation closer to the hospital. Your hospital team might be able to help you arrange this.

You will need to have someone with you at all times until 4 weeks after your CAR-T infusion because of the possibility of delayed side effects. You will be told not to drive or operate heavy machinery for 8 weeks after treatment.

Your medical team will tell you what to look out for and who to contact if you have any concerns.

“ Thankfully, I experienced minimal side effects and after two weeks in hospital I was moved to NHS accommodation nearby as I still had to have daily blood tests, and there were days where I needed platelets or blood transfusions. Two weeks after leaving hospital, my bloods had settled sufficiently and I was able to go home.



Rachel, treated with CAR-T cell therapy for diffuse large B-cell lymphoma



Side effects

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“ *I had a lot of side effects, including rigor attacks, confusion and fever. I had to be nursed really, I had to be looked after. Every day my medical team assessed my cognitive abilities. To me, having side effects showed that the CAR-T cell therapy was working.*

Fiona, treated with CAR-T cell therapy for diffuse large B-cell lymphoma



Side effects of CAR-T cell therapy

CAR-T cell therapy can cause serious side effects. Around 1 in 5 people who have CAR-T cell therapy need treatment in an intensive care unit (ICU).

CAR-T cell therapy is only given in hospitals with the facilities and staff to treat side effects effectively. You are monitored closely in hospital with regular blood tests after having CAR-T cell treatment. You stay close to the hospital for a period of time afterwards so that you can be treated quickly if you develop any side effects.

The most common side effects of CAR-T cell therapy include:

- cytokine release syndrome
- neurotoxicity (known as ICANS)
- low blood counts and risk of infection.

This is not a complete list of side effects. You are likely to also experience side-effects of the lymphodepleting chemotherapy, such as fatigue and nausea. Your medical team should tell you about the side effects you might experience and how to manage them. Ask as many questions as you want to make sure you understand everything.

Tell your medical team about any side effects you have or if you feel unwell during your treatment. There are often things they can do to help.

Find out more about side-effects at lymphoma-action.org.uk/SideEffects

“ I had lost a lot of weight and couldn't eat and felt at a really low ebb. As well as the extreme weight loss, I was also feeling very fatigued. I was monitored really closely once the CAR-T cells had been given to me, checking my temperature, my blood counts and my cognitive ability. I was having tests every day. If I'd had inhibitions before this, they all went through the window!

John, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

Cytokine release syndrome

One of the most common complications of CAR-T cell therapy is called '**cytokine release syndrome**' (CRS).

CRS happens when CAR-T cells are activated and release chemicals called cytokines. These cytokines activate other immune cells, which also release cytokines. When lots of cytokines are released at once, they can overwhelm your body.

Signs and symptoms of CRS include:

- fever and chills
- rapid heart rate
- low blood pressure
- low oxygen levels in your body (symptoms include headache, difficulty breathing, rapid heart rate and bluish colour on skin)
- headache
- feeling or being sick.

Almost everyone treated with CAR-T cell therapy experiences some level of CRS. It most commonly develops within 10 days of having your CAR-T cells. Most cases are mild or moderate and easily treated. However, severe or life-threatening reactions can occur.

Your medical team will monitor you very closely to identify CRS quickly and treat you as soon as symptoms arise. You might be given steroids and a drug called tocilizumab, which helps dampen down the immune response. If you have a severe reaction, you might be transferred to the intensive care unit for treatments such as oxygen and fluids.

With treatment, CRS usually gets better within a few days.

Neurotoxicity

When lots of CAR-T cells are activated, they release chemicals that can affect your nervous system. This is called ICANS (immune effector cell-associated neurotoxicity syndrome).

Symptoms of ICANS include:

- confusion
- drowsiness
- speech problems
- mood changes
- difficulty writing
- headaches and dizziness
- shaking or tremor
- movement difficulty.

Around half of people treated with CAR-T cell therapy experience ICANS. It generally develops within 28 days of having your CAR-T cells, often within just a few days. Symptoms are usually mild and get better on their own in a week or two.

Around 1 in 5 people have more serious symptoms such as seizures (fits) or life-threatening problems such as swelling of the brain. Your medical team will monitor you closely so they can start treatment quickly if you need it.

If you have serious symptoms, you might need steroids and be admitted to the intensive care unit. Most people improve within a few days of treatment.

Low blood counts and risk of infection

A combination of chemotherapy and CAR-T cell therapy often leads to low **blood counts**. Most people have low blood counts during the first month after CAR-T cell therapy. Around 1 in 4 people have low blood counts that last several months.

You will have regular blood tests to check your blood counts. If your blood counts are very low or are causing problems, you might need blood transfusions or growth factors to help boost them.



Find out more about blood transfusions and growth factors on our website, lymphoma-action.org.uk/Treatment

Neutropenia and B-cell aplasia (low white blood cell count)

After CAR-T cell therapy, your levels of a type of **white blood cell** called a B cell are likely to be low for a long time – sometimes several years. **B cells** make **antibodies**. Having a low B cell count and low antibody levels increases your risk of developing an infection.

You will be given antibiotics and antiviral medicines to prevent infections ('prophylactic' treatment). If you have very low antibody levels, you might need treatment with donor antibodies (immunoglobulin replacement therapy).

Tips to help lower your risk of infection

Keep good personal hygiene

- Wash your hands before eating and after using the toilet. Take antibacterial hand sanitiser gel or wipes with you if you are out and about.

- Have a warm bath or shower each day. Check with your clinical team for advice about bathing and showering if you have a chemotherapy central line (central venous catheter) in place.
- Keep good dental hygiene. Use a soft toothbrush and an alcohol-free antiseptic or antibacterial mouthwash.

Minimise contact with germs

- Avoid places where you have a higher risk of catching an infection, such as swimming pools, busy shops and public transport at peak times.
- Avoid contact with people who are unwell, for example with a cold, tummy bug or chickenpox.
- Prepare food safely and don't eat anything that is past its sell-by-date – use refrigerated food within 24 hours of opening. You can find out more about food safety on the World Health Organisation (WHO) website and the Food Standards Agency website.
- Take care when handling pets – avoid bites or scratches and wash your hands after any contact with an animal. If possible, ask someone else to deal with pet care jobs that involve animal poo, such as cleaning out litter trays.
- Visit your dentist before you start treatment for lymphoma – you might not be able to have any dental work done during or soon after treatment because of increased risk of infection.

Protect your skin

- Protect yourself from cuts and scratches by wearing gloves for gardening, wearing shoes when you are outside and avoiding walking barefoot indoors.
- Keep your skin moisturised with a simple body lotion or moisturiser if it becomes dry or cracked.
- Allow spots and scabs to heal without picking at them.

“ Following CAR-T cell therapy, I became severely immunosuppressed but I started immunoglobulin therapy which helped support my immune system. This improved my wellbeing and confidence when mixing with others.



Rachel, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

If you do get an infection, it can be serious, sometimes even life-threatening. An infection in someone with **neutropenia** needs urgent treatment. You usually have to stay in hospital for intravenous (IV) antibiotics and careful monitoring.

While you are in hospital, your medical team monitor you closely for signs of infection. When you go home, they will tell you what signs to look out for and who to contact if you are worried you might have an infection.

Contact your medical team straightaway if you have any signs of infection. It is important to get treatment promptly.

Possible symptoms and signs of infection include, but are not limited to:

- fever (temperature above 38°C/100.4°F)
- hypothermia (temperature below 35°C/95°F)
- shivering or rigors (even if you do not have a fever, which is more likely if you're taking steroid medication)
- chills and sweating
- feeling generally unwell, confused or disoriented
- blocked nose, earache, sore throat or mouth
- cough, yellow or green phlegm or snot (mucus), difficulty breathing
- redness and/or swelling of the skin, pain and redness around intravenous (IV) lines
- diarrhoea or vomiting
- a feeling of burning or stinging when you wee, or needing to wee more often than usual
- vaginal discharge or itching
- unusual and new stiffness of the neck with discomfort around bright lights
- new and increasing pain.

Contact your medical team if you have any of these signs or symptoms, however minor they might seem.

Anaemia (low red blood cell count)

If you have a low **red blood cell** count, you don't have enough haemoglobin (the cells that carry oxygen around your body). This is called **anaemia**. It might make you feel tired or short of breath. If your red blood cell count is very low, you might need treatment with a blood **transfusion** – a drip (infusion) of donated blood or blood products given into one of your veins.

Possible symptoms and signs of anaemia include:

- shortness of breath
- feeling unusually tired
- dizziness
- new aches and pains, especially cramps in your legs when you walk or sleep.

Tell your doctor if you have any of these symptoms as this could be a sign of anaemia that needs treatment.

Thrombocytopenia (low platelet count)

Thrombocytopenia is a shortage of platelets. You might bruise easily, bleed more or bleed for longer than usual if you hurt yourself if you are thrombocytopenic.

If your platelet count is very low, or you are at particular risk of bleeding, your clinical team might adjust your treatment or offer treatments to help your blood clot. In some cases, a transfusion of **platelets** is needed.

Possible symptoms and signs of thrombocytopenia include:

- nosebleeds
- bleeding gums after brushing your teeth
- heavier or longer periods than is usual for you
- bleeding for longer than you'd expect after a cut or scratch
- bruising more easily than usual
- red or purple patches or spots called 'purpura' or 'petechiae' on your skin (often on your legs), your lips or in your mouth
- blood in your sick (vomit)
- blood in your wee
- blood in your poo (this might be obvious, bright red blood or it can make your poo black and sticky)
- persistent headache, blurred vision or a change in your level of consciousness.

Contact your medical team if you develop any of these symptoms.

If you have a low platelet count, take precautions to reduce your risk of bleeding. For example, avoid contact sports (such as rugby) and high-impact sports (such as football and martial arts). Wear gloves to protect yourself from injury while doing activities such as gardening, DIY and crafts such as sewing.



After CAR-T cell therapy

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“ *Any time I need my cancer team or have any concerns I can call them and if they want me to come in, they book me in for bloods.*

Zoe, treated with CAR-T cell therapy for primary mediastinal large B-cell lymphoma

Follow-up

You have regular follow-up appointments with your CAR-T team and your local haematology team after you go home. Your appointments get less frequent as time goes on.

The aim of follow-up is to:

- check your recovery
- help you manage any side effects of treatment
- give you a chance to ask questions and talk about any concerns you have
- check for signs of relapse.

During follow-up, your doctors will ask how you're feeling. You might also have physical examinations and blood tests. You will usually have a PET/CT scan to assess your response to treatment 1 month and 3 months after having your CAR-T cells. You might also have an additional scan at 6 months after treatment.



Find out more about tests and scans at lymphoma-action.org.uk/Tests

“ I went on to have further PET/CT scans at three months and six months post CAR-T cell therapy. I felt very apprehensive during this time, hoping the treatment had been successful. But I am pleased to say that I have now been in remission for over four years.



Rachel, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

You can contact your medical team at any time. Don't wait until your next appointment if you start to feel unwell or are worried about your recovery.

Feelings and emotions

There is no right or wrong way to feel, and there is support available, no matter how you are feeling. After CAR-T cell therapy you are likely to experience a range of thoughts and emotions, some of which might feel strange or unfamiliar.

“ I was alone on a beach listening to the waves when I was told I was in complete remission. On that beach, at that moment, I had been told the best news ever! That was such a special moment, but since then I have had low days, especially the week after I was told about the remission. I found myself reflecting on everything I have been through – the endless appointments, the 22 tablets a day and the chemotherapy drugs. But then it just stops and I felt lost in a way. I asked my wife ‘Why do I feel so low when I have just had the best news?’



Matthew, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

“ I documented everything on TikTok which really helped me think about how I was feeling.

Zoe, treated with CAR-T cell therapy for primary mediastinal large B-cell lymphoma



Recovery and day-to-day living

CAR-T cell therapy can affect you physically, emotionally and practically. It can take a long time to fully recover. Your medical team should work with you to identify and address your needs. This might involve a ‘holistic needs assessment (HNA)’.



Learn more about the support available after treatment for lymphoma at lymphoma-action.org.uk/Recovery

Having CAR-T cell therapy affects everybody differently. You might find that it affects you in ways you didn’t expect. You might need to make changes to your everyday life to help you cope. Some people call this finding their ‘new normal’.

Talking to other people can help you make sense of challenging feelings. You could speak to a family member or friend. You could also speak to a member of our Helpline Services team, or consider getting support from a counsellor.

We're here to support you however you're affected by lymphoma. Call our Helpline Services on freephone 0808 808 5555, 10am to 3pm, Monday to Friday.

We have a range of ways we can support you – see page 52.



We have more information on day-to-day living in our book *Living with and beyond lymphoma*. Download or order a free copy from lymphoma-action.org.uk/Books

Following a healthy lifestyle puts you in the best position to live well, with and beyond lymphoma. This includes:

- eating a healthy, balanced diet with a wide variety of foods
- keeping your body at a healthy weight
- drinking plenty of fluids
- not smoking
- keeping active
- protecting your skin from the sun
- getting plenty of rest and sleep
- going for any health tests or screenings you're offered.

After having CAR-T cell therapy, you might lose your immunity to illnesses you have been vaccinated against in the past. Your medical team might recommend that you repeat these vaccinations. They will tell you what they recommend depending on your individual circumstances.

Late effects

Late effects are health problems that develop months or years after treatment for lymphoma. Your medical team should talk to you about the possible late effects of your treatment before it starts.

While it's not possible to say for certain whether you'll develop late effects, your medical team can give you an idea

“ *I started having my childhood immunisations all over again to help rebuild my system. When I returned to work I soon realised that I could no longer work the hours I used to, mainly due to fatigue. There is definitely a limit on how much I can do on a day-to-day basis, which I recognise, so I now work on a part-time basis, two days a week which gives me time to enjoy life and spend time with family and friends.*



Rachel, treated with CAR-T cell therapy for diffuse large B-cell lymphoma

based on your specific lymphoma, the treatment you've had and individual risk factors, such as your age and lifestyle. You can't always prevent late effects but noticing problems early gives you a better chance of treating or managing them effectively.

As CAR-T cell therapy is still a relatively new treatment, your medical team will continue to monitor you for many years after treatment to monitor for any unexpected late effects.



We outline some of the possible late effects below. You can find more information on our website lymphoma-action.org.uk/LateEffects

Low blood cell counts and antibody levels

Low blood cell counts, a condition called B cell aplasia, and low levels of antibodies in your blood (hypogammaglobulinaemia), can all be long term effects of having CAR-T cell therapy.

These conditions can greatly increase your risk of infection. This can be managed by taking steps to reduce your chances of getting an infection, see page 30.

Treatment can include blood product transfusion, prophylactic antibiotics, immunoglobulin replacement therapy and growth factor support depending on which blood cell counts are low.



Find out more about these treatments at lymphoma-action.org.uk/Treatment

Other cancers

Treatment for lymphoma can increase your risk of developing another cancer in the future. However, this risk is still small.

The type of cancer you might be at risk of depends on lots of factors, including the type of lymphoma you have, the exact treatment you've had, how old you were when you were treated and how old you are now.

Lifestyle factors also affect your risk. If you are a smoker, consider giving up. Eating a healthy diet, maintaining a healthy weight and ensuring you protect your skin from the sun can all help to reduce your risk.

Talk to your medical team about what to look out for in the future. Cancer is usually more treatable if it is diagnosed early.

If lymphoma comes back

If your lymphoma comes back (relapses) after CAR-T cell therapy, your treatment options depend on lots of factors. These include the type of lymphoma you have, the treatments you've already had and your general health. Your specialist can give you more information about your options.

Questions to ask your medical team

The health professionals in your medical team are best placed to give you information specific to your individual situation.

Note down the information you get during your appointments. You could ask whether you can make an audio recording of the consultation. Sometimes health professionals might use terms that are unfamiliar to people who don't have medical training. If you don't understand something, ask for a simpler explanation.

If possible take someone with you to appointments, both for emotional support and to help remember key points.

It can be helpful to write down questions and take them to your appointment. Here are some suggestions.

Deciding to have CAR-T cell therapy

- Why are you suggesting CAR-T cell therapy for me?
- How successful is CAR-T cell therapy likely to be?
- What alternative treatment options are there?

Having CAR-T cell therapy

- Where will I have the treatment?
- How long am I likely to need to stay in hospital?
- How do I find accommodation near the hospital?
- Can I have visitors whilst in hospital?
- How many appointments will I need to attend?
- What emotional support is available to me at this time?

Side-effects of CAR-T cell therapy

- What side effects am I likely to experience?
- How long can side effects last?
- Can you do anything to help manage the side effects?
- Will CAR-T cell therapy affect my fertility?
- Can I drink alcohol?

After CAR-T cell therapy

- Can I have sex after CAR-T cell treatment?
- Can I travel to another country after CAR-T cell therapy?
- How will we know if CAR-T cell therapy is working?
- What late effects should I look out for?
- What options are available if CAR-T cell therapy isn't successful?
- What emotional support is available to me at this time?

Find out who you should contact if you have any concerns or if you have any more questions. Write down any key contact names and phone numbers on page 3 of this book.

Glossary

Anaemia	shortage of haemoglobin (or red blood cells) in your blood stream	Cytokine release syndrome	an immune reaction to some types of immunotherapy (for example, CAR-T cell therapy) that causes a rapid release of chemicals called cytokines which can overwhelm your body
Antibody	a specialised protein made by white blood cells that helps to fight infections by sticking to proteins on the surface of cells that don't belong in your body, such as viruses, bacteria or some cancer cells	Growth factors	naturally occurring chemical messengers (hormones) that encourage blood cells to divide and develop. There are different growth factors to encourage different types of blood cell to develop (for example, GCS-F, EPO, TPO)
B cells / B lymphocytes	a type of white blood cell (an immune cell) that fights infection by producing antibodies	Haemoglobin	a protein in red blood cells that carries oxygen around the body
Blood count	the number of each type of blood cell in your blood	Immunotherapy	antibody therapy that activates the immune system to destroy lymphoma cells
CAR-T cell therapy	treatment that uses your own immune system to recognise and kill lymphoma cells. Your own T cells are collected and genetically modified so they recognise and stick to a particular protein on the surface of your lymphoma cells	Infusion	having a fluid (other than blood) given into a vein
Chemotherapy	a type of treatment for lymphoma that uses drugs to damage and kill rapidly dividing cells at various stages of their cycle of development	Late effects	health problems that develop months or years after treatment has ended
		Lymphocytes	a type of cell that grows out of control if you have lymphoma. There are three main types of lymphocyte – B cells, T cells and natural killer cells

Lymphoma	cancer of the blood that develops when lymphocytes (a type of white blood cell) grow out of control	Thrombocytopenia	a shortage of platelets in the blood that increases the likelihood of bruising and/or bleeding
Neutropenia	low levels of neutrophils (a kind of white blood cell) in the blood; can result in the body allowing infections to develop	Transfusion	having blood or blood products given to you through a drip into one of your veins
Platelets	a type of blood cell that helps your blood to clot	White blood cell	a cell found in the blood and in many other tissues that helps our bodies to fight infections. There are several different types, including lymphocytes and neutrophils.
Radiotherapy	a type of treatment for lymphoma that uses radiation to destroy cancer cells		
Red blood cells	cells in your bloodstream that carry oxygen around the body; also called 'erythrocytes'		
Refractory	lymphoma that does not respond well to the first choice of treatment		
Relapse	lymphoma that comes back after successful treatment and a period of remission		
T cells / T lymphocytes	immune cells that are made in your bone marrow and develop in your thymus, which help to protect us from viruses and cancers by attacking them directly		

Information and support

If you or someone you love is affected by lymphoma, we're here to support you. We have a range of support services that are free to access. Find out more at lymphoma-action.org.uk/support-you



Helpline: a freephone helpline available Monday to Friday, 10am to 3pm on 0808 808 5555, or use Live Chat on our website.



Online Support Meetings: a safe place to connect with others affected by lymphoma



Facebook Support Group: our UK-wide group is for anyone affected by lymphoma



Buddy Service: peer support from someone with similar lived-experience of lymphoma



TrialsLink: our database of clinical trials



Preparing for Treatment Service: online support and information to help you prepare for treatment.

For our latest news and updates, follow us on social media:

  @lymphomaaction    lymphoma_action

If you're interested in finding out more about lymphoma, we have lots more information on our website, including videos and podcasts.

We also produce a number of books, which are available free of charge, including:

- *Introduction to lymphoma*
- *High-grade non-Hodgkin lymphoma*
- *Low-grade non-Hodgkin lymphoma*
- *Young person's guide to lymphoma*
- *Living with and beyond lymphoma*
- *When someone close to you has lymphoma*
- *Easy Read books.*

Find our full range of books and information at lymphoma-action.org.uk/Books or call us on 0808 808 5555.

Our information is evidence-based, approved by experts and reviewed by users. We have been awarded the PIF TICK – the UK's only assessed quality mark for printed and online health and care information. By keeping up-to-date with latest developments, we ensure that our information stays relevant and reflects current practice. Learn more at lymphoma-action.org.uk/HealthInfo



Useful organisations

We list some organisations below that you might find helpful. Search online for the name of the organisation to find their websites. If you don't find what you are looking for, please contact our Helpline (page 52).

Anthony Nolan provides information and support for people with blood cancer and their families.

British Association for Counselling and Psychotherapy provides a list of accredited counsellors in your area.

Cancer Research UK has information on all types of cancer and a nurse-led helpline: 0800 800 4040.

Carers UK offers advice, information and support for carers.

Macmillan Cancer Support provides practical, emotional and financial support to people affected by cancer.

Maggie's provides practical, emotional and social support to people with cancer and their family and friends.

Mind offers support and advice to anyone experiencing a mental health problem.



Visit lymphoma-action.org.uk/UsefulOrgs for a list of other organisations you might find helpful.

How you can help us

Volunteers are at the heart of what we do. By giving your time, you can help us make a meaningful difference to people affected by lymphoma and be part of our valued volunteer community. If you'd like to volunteer with us, visit lymphoma-action.org.uk/Volunteering

We continually strive to improve our resources and are interested in any feedback you might have. Please visit our website at lymphoma-action.org.uk/BookFeedback or email us at publications@lymphoma-action.org.uk with any comments. You can also call our Information and Support Team on 0808 808 5555.

Can you spare five minutes to give feedback on this book? It will help us plan future versions. Please scan the QR code to complete our short survey.



References

The full list of references for this book is available on request. Please email publications@lymphoma-action.org.uk or call 01296 619400 if you would like a copy.

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Notes



Notes



This book has been researched and written by Lymphoma Action, the only UK charity dedicated to people affected by lymphoma.

We would like to thank our incredible supporters whose generous donations enable us to offer our essential support services free of charge. As an organisation we do not receive any government or NHS funding and so every penny received is truly valued.

To make a donation towards our work please visit lymphoma-action.org.uk/Donate

This book explains what CAR-T cell therapy is and what to expect if you, or someone you know, is having it to treat lymphoma.

Lymphoma Action is a charity that has been providing information and support to people affected by lymphoma for over 35 years.

We're here for you.



Freephone helpline **0808 808 5555**
(Mon to Fri, 10am to 3pm)



information@lymphoma-action.org.uk



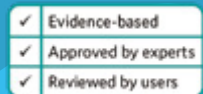
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Live Chat via our website
(Mon to Fri, 10am to 3pm)

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Lymphoma Action
Unit 3, Bell Business Park
Smeaton Close, Aylesbury
Bucks HP19 8JR
General enquiries 01296 619400



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