

lymphoma matters

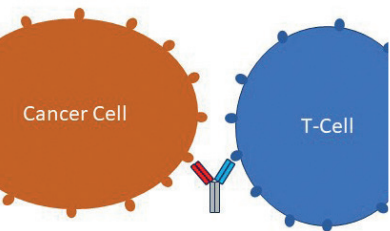
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for over 35 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment, and aftercare of lymphoma. We're here for you.

Views expressed are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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If you would like to make a donation towards our work please:

- Complete and return the form on the covering letter, using the Freepost envelope provided
- Visit lymphoma-action.org.uk/Donate
- Call us on 01296 619400

With thanks to Abbvie, BMS Celgene, Eli Lilly & Company, Roche UK, Sobi, Serb Pharmaceuticals and Takeda UK Ltd for funding this issue of *Lymphoma Matters*. As per our policy they have no influence over our content.





Ropinder Gill
Chief Executive

Find out more
about vaccinations
available this
autumn and winter
on page 6.



We hope you like this
edition of *Lymphoma
Matters*. You can sign up
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magazine at
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Sign-Up](https://lymphoma-action.org.uk/Sign-Up)

Looking forward to new developments

Welcome to this edition of *Lymphoma Matters*. As well as sharing stories, we hope that it will give you a flavour of some of the developments in treatment options for people diagnosed with lymphoma. We monitor the treatment landscape carefully and represent the patient voice where we can, as we know therapies can dramatically improve quality of life for many people.

The availability of more treatment options means more for healthcare professionals, like our new trustee Chrissie, to understand and discuss with their patients. It's more choice and more complexity in a stretched NHS service. We aim to inform, support and connect not just people affected by lymphoma but also healthcare professionals who make all the difference in someone's experience of care and treatment.

This Autumn our flagship Lymphoma Management Course is taking place over four consecutive weeks providing educational content to nearly 400 registrars, consultants and lymphoma specialists.

So, thank you for your support. It is only through your generosity that we can provide information and support services, monitor and input into treatment developments and support healthcare professionals.

We look forward to telling you more in future *Lymphoma Matters* about these areas of work.

Ropinder Gill
Chief Executive



@lymphomaaction



lymphoma_action

Lymphoma Action welcomes new Trustee

We are pleased to welcome Chrissie Kirby as a Trustee of Lymphoma Action.

Chrissie is a Haematology Clinical Nurse Specialist (CNS) with a specialist interest in lymphoma. She is based at Hampshire Hospitals NHS Foundation Trust and leads the service in Basingstoke and North Hampshire Hospital.

Chrissie qualified as a nurse in 2014, becoming a Haematology CNS in 2018, as well as the Teenage and Young Adult (TYA) cancer lead nurse.



“I am excited to bring my clinical knowledge and skills to the team. I have always used Lymphoma Action as a resource for my patients and their families, so I know how important the charity is, and am very excited to be able to support and be a part of their continued success.



Watch our new animation Lymphoma Symptoms

We are delighted to launch a new animation entitled *Lymphoma Symptoms*.

This short animation clearly explains the common symptoms of lymphoma. We hope it will help empower people to ask questions and have conversations with their medical team about their health.

To watch our animation, search ‘Symptoms’ on our website.



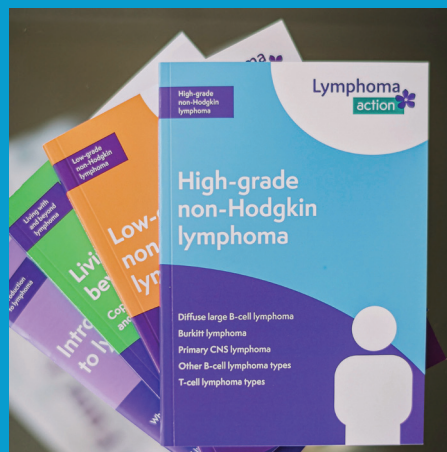
We are grateful to Consultant Haematologists Professor Graham Collins and Dr Cathy Burton who worked with us to ensure the information contained in this animation is accurate.

Updated *High-grade non-Hodgkin lymphoma* book

Are you, or someone you love, affected by a high-grade non-Hodgkin lymphoma? Our revised book covers diffuse large B-cell lymphoma, Burkitt lymphoma, T-cell lymphomas and primary CNS lymphoma. We've worked with experts to update our book, which describes how high-grade non-Hodgkin lymphoma affects people, how it is treated and what to expect during and after treatment. This latest edition has new personal experience quotes as well as practical tips. You can download the book or order a copy free of charge through our shop.

“ I think that these books are a fantastic resource and the best balance between providing clear information while not making it impenetrable and overwhelming. I use the illustrations all the time in clinic to explain the lymphoid system and staging and it really helps.

Dr Eve Gallop Evans, Consultant Clinical Oncologist



Our latest podcast shines a light on NICE

In our latest podcast Helen Knight (*right*), Director of Medicines Evaluation at the National Institute for Health and Care Excellence (NICE) explains the role of NICE in the development and availability of new treatments. Talking to Lymphoma Action's Tara Steeds (*left*) Helen explains in detail about what health technology assessments (HTAs) are. She also talks about the role stakeholders and patient organisations, such as Lymphoma Action, have in ensuring NICE has a clear picture on what the question is that needs to be answered by the treatments being assessed. As Helen explains, 'NICE drives innovation into the hands of health practitioners.'



Listen to the podcast at lymphoma-action.org.uk/Podcast#NICEpodcast



Vaccination update

Should I have the flu jab?

The flu vaccine is given free on the NHS including to people with certain health conditions, (this includes lymphoma), people over 65, people who live with someone who is more likely to get a severe infection due to a weakened immune system, people who live in long-stay residential care and those who receive carers allowance.

You are recommended to have an annual influenza vaccine or 'flu jab' if you have lymphoma, if you have had your spleen removed (splenectomy), if you are having chemotherapy, steroids or radiotherapy. These can suppress your immune system, making you more vulnerable to flu. People who are in close contact with you should also have the flu jab.

The timing of the flu jab is important. Ideally people should have this before they start treatment, because once on treatments such as rituximab, there is evidence to suggest that the flu vaccine is not as effective.

You need to be vaccinated every year as each year's vaccine is developed based on the virus strains experts think most likely to be around in the coming year. If you are attending hospital regularly for treatment, you may be able to have the flu jab there; otherwise ask your local GP surgery. The flu vaccine does not contain live virus, so you cannot catch flu from having the jab.

Important advice:

- Aim to have the flu vaccination before you commence treatment.
- If you are on treatment, ask your medical team about the best time for you to have the vaccination.
- If you have had a transplant, you should receive the flu vaccination 6 months post-treatment and annually thereafter.
- Some children have the nasal flu vaccine. This is a live vaccine so you should avoid children who have had it for 2 weeks following their vaccination if your immune system is weakened.

Seasonal COVID-19 autumn booster

Since 1 July 2023 the UK changed its COVID-19 vaccination programme to mainly a seasonal booster campaign. Vaccinations are still the best way to offer protection from COVID-19 but this protection fades over time; this protection is boosted with the seasonal vaccination.

If you are at increased risk of getting seriously ill from COVID-19, you should be offered a seasonal booster. Specific groups eligible are:

- Residents in a care home for older adults
- All adults aged 65 years and over
- People aged 6 months to 64 years in a clinical risk group
- Frontline health and social care workers
- People aged 12 to 64 years who are household contacts of people with immunosuppression
- People aged 16 to 64 years who are carers and staff working in care homes for older adults.

If you are eligible, the NHS will be in touch with you and then you will be able to either book a vaccination online, get it at your GP surgery or care home, or attend a walk-in vaccination site. If you are not invited for one but believe that you are eligible then speak to your specialist team or GP.

The shingles vaccine

The shingles vaccine helps protect against shingles. It is recommended for people at higher risk from shingles. This includes those who are 70 to 79 years of age with a weakened immune system and those aged 50 and over with a severely weakened immune system.

Until 2021, the only vaccine available in the UK was Zostavax® which is based on a live but weakened version of varicella zoster virus (the virus that causes shingles). This is not suitable for people with low immune systems because it could cause shingles infection.

A vaccine called Shingrix® is now available for people with lowered immunity. This contains a protein made by the varicella zoster virus but it does not contain the virus itself. It cannot cause shingles.

If you are eligible for shingles vaccination, you should be contacted by your GP. Shingrix® is a one-off course of vaccination given as two doses, at least 8 weeks apart. You do not have annual boosters.

We are grateful to Dr Cathy Burton, Consultant Haematologist, St James's University Hospital Leeds, for reviewing this article.

Naomi talks about her diagnosis of Hodgkin lymphoma and the importance of knowing the signs of neutropenic sepsis



In May 2022 life was really good. I was 32, married with a 2-year-old daughter and, having qualified as an English teacher, was working as a Special Educational Needs Co-ordinator (SENCO).

While having a shower I noticed a lump which felt about the size of a golf ball. I had no symptoms whatsoever and at first wondered if I was imagining things. I did a search on Google which indicated that it could be as a result of an infection. I also read that if a lump doesn't go down within two weeks, seek medical advice.

The lump didn't go and a visit to my GP resulted in being referred to hospital for various tests, including blood tests and an ultrasound scan. This was followed by a laryngoscopy and a biopsy of the lump. While waiting for the results of these tests, I did a lot of research, trying to avoid catastrophising what it could be. I didn't think about cancer.

I was at work when a call came through with the results. The doctor explained that the results had revealed lymphoma. He explained that someone from the haematology team would call me, but it meant that I spent over a week wondering what type of lymphoma I had. It was a really worrying time. I was diagnosed with stage 3 Hodgkin lymphoma.

All I could think about was my husband and daughter. What could I say to them? My husband was understandably quite shocked and upset and we talked about how we were going to approach things. We agreed to try and keep things as normal as possible for our daughter and decided we would only tell family and close friends. At work, I only told the leadership team.

I had previously had an infected wisdom tooth, which I had informed my team about. The consultant told me it was

important for me to have my teeth looked at before treatment to avoid complications and the risk of infection. I ended up having all four wisdom teeth removed under local anaesthetic just five days before chemotherapy started.

I had large masses on my chest. I had two intensive cycles of chemotherapy (escalated BEACOPP). After these I had a PET/CT that revealed I was in remission. My treatment was then de-escalated to AVD and a scan at the end of treatment showed no evidence of lymphoma. I felt a mix of feeling ecstatic, surprised and confused as I had only just got my head around things.

During this time I continued my role as a SENCO, and I was able to continue working at home whilst having treatment for the most part. I found working a welcome distraction from everything that was going on. The leadership team at work were incredibly helpful during this time, particularly my head teacher, who was really supportive throughout my illness.

I had been made aware I would be more susceptible to infections due to having a low immunity. In November, I felt really unwell, feeling even more fatigued than usual and really struggling to do anything. I had no appetite and had a high temperature. In my mind, I thought this was just because of the chemotherapy, so decided to give it a couple of days to see if I felt better. On the morning I ended up in hospital I was home alone with my daughter and had already blacked out twice. I could only crawl and felt incredibly dizzy and it dawned on me that this feeling was

not OK. I ended up laying on the kitchen floor in septic shock, with my daughter beside me.

My husband came home and rushed me to hospital, where they told me I had neutropenic sepsis. I was rushed into resus and ended up in hospital for 8 days with sepsis the first time. I was discharged on the day of my daughter's 3rd birthday party, so I could attend. This gave me a well needed boost.

I was shocked by just how quickly I had become seriously ill and by then it was difficult to do anything about it. Once I had recovered from the sepsis I was able to have the last four cycles of AVD chemotherapy, which finished in the middle of March 2023.

“ I actually had sepsis twice.

The second time I had sepsis, I had a feeling it was sepsis due to knowing what to look out for and I only had to stay in for 4 days. Spotting the signs earlier meant it was caught and treated and was not as life-threatening.

I was really pleased treatment had finished, but it felt like my safety blanket had gone. I am seeing the team at follow-up appointments and know I can contact them with any concerns which I did when I felt something in my neck again. It is a worry that the cancer could come back or even that I could get a different type of cancer, but I cannot dwell on this, and I try to remain as positive as I can about my life. This has been one of the motivations to me writing a book about my experiences.

“ Keeping a journal really helped

One of the things I have found has really helped me throughout my experience has been keeping a journal. My mother-in-law gave me a wellbeing diary when I had my diagnosis and I have used it as a journal to put down all my thoughts and feelings; particularly things that have frustrated me. I suppose as an English teacher writing thoughts and poems is a natural thing for me.

I am a reflective person and as treatment finished I found that I have thought a lot about how I am feeling. I reflect on what I have gone through, getting better and being well is a priority. I do want to get back to doing all the things I did before and take the time needed to recover. I am pleased to be able to do more things with my daughter now and glad to be back to work as normal.

“ Treatment has changed my body, at least for now

It's still early days and I am starting to feel like my body is coming back to me. Although my hair is starting to come back, looking in the mirror and seeing my hair is still a daily reminder of what I have gone through. I know it's quite a superficial thing, but my hair was such a large part of me and losing it made me feel like a sick person.

At the moment I feel old. I get stiff very quickly and I feel aches and pains even if I'm just sitting on my sofa or at my laptop. Mentally, I know my brain doesn't feel the same.

My short-term memory is not great at the moment, so I write everything down and I have to be told things several times before the information really sinks in. But things are improving slowly and my energy levels are getting better and being more active is helping with my recovery.

I have put a lot of pressure on myself to get back to how I was before my diagnosis of Hodgkin lymphoma, but I am slowly realising that I am at the beginning of recovery and that it's going to take time. For now, I just need to stop putting so much pressure on myself, take the time needed to recover fully, whilst getting back to normality and living life to the full.

Using the poems I wrote about my experiences, I have written a book that has been published. I wanted to share my experiences in order to help others and raise awareness of lymphoma and sepsis. I feel this is a big part of my story as it has turned something that was devastating into something positive.

To read Naomi's poetry, search Amazon for 'The C Word: Poetry Collection' by Naomi Flaherty.





Sepsis – know the signs

Sepsis is a serious, whole-body reaction triggered by an infection. Neutropenic sepsis is sepsis in someone who has a low neutrophil count (neutropenia). It is sometimes called 'febrile neutropenia' too.

People with neutropenia have a higher-than-usual risk of getting an infection and can develop sepsis much more quickly than normal. People having stronger chemotherapy are more at risk of this happening as their blood count can be very low, but it can affect people having quite gentle treatment. If it does develop, it is serious, possibly life-threatening, and must be treated urgently.

Always seek help quickly if you might be neutropenic and feel unwell.

The most common sign of sepsis, whether or not someone is neutropenic, is a raised temperature. If you are having treatment for lymphoma, try to keep a thermometer handy so you can measure your temperature accurately. Contact your hospital at once if your temperature is 37.5°C or more on two occasions within an hour or as per your local hospital's guideline. Sepsis doesn't always cause a high temperature though, especially if someone is taking steroids.

Symptoms of sepsis and infection can include:

- a temperature of 37.5°C or more
- shivering episodes
- a fast heartbeat or breathing
- cough, sore throat or mouth, earache
- a burning sensation when passing urine
- weeing less than usual
- feeling generally unwell, dizzy, confused or disorientated
- redness and swelling around skin sores, injuries or intravenous lines
- unusual stiffness of the neck and difficulty with bright lights.
- a low temperature below 35°C
- chills and sweating
- clammy, cold, pale or mottled skin
- diarrhoea, nausea or vomiting
- unusual vaginal discharge or itching
- loss of consciousness

Contact your hospital team immediately if you have any of these symptoms, no matter how mild or vague they may seem. Always seek help quickly if you might be neutropenic and feel unwell.

Thanks to Charlotte Bloodworth, Advanced Nurse Practitioner, for reviewing this.

Christmas shop

Our Christmas Cards are now available and we've included a brochure for you to place your orders.

You can shop online where we have some fab stocking fillers and gifts for your loved ones. Giving a present to someone means a lot, and giving a Lymphoma Action gift means twice as much, as you will be making a difference to all those affected by lymphoma!



So pick up your cards, pop in some seeds of thanks, add a fabulous branded dog bandana, cosy bobble hat and brilliant golf umbrella and your Christmas shopping will already be off to a great start!

www.charitycardshop.com/LymphomaAction

Light a star

Light a Star for someone special this year.



Remember a loved one and let their memory shine. The Christmas period is a time to reflect and remember those special people in our lives. By lighting a star, you will be helping to shine a light on the UK's fifth most common cancer.

Simply visit our dedication page lymphoma-action.memorypage.org/lightastar2023, email fundraising@lymphoma-action.org.uk, call the Fundraising Team on 01296 619400, or use our QR code above.

Big Give 2023

28 November – 5 December

Once again, we are taking part in this year's Big Give Christmas Challenge. We're aiming to raise £20,000 through this year's campaign, to help fund our new 'Preparing for Treatment' Service. This service, launching next year, will prepare people with lymphoma for treatment, both physically and emotionally.

If you make a donation to Lymphoma Action via the Big Give Christmas Challenge website **during the week of 28 November to 5 December**, your donation will be doubled at no cost to you! That's one donation, twice the impact. Your donations can only be doubled while the match funding providing by our generous Big Give funders lasts.

So please make a note of **28 November to 5 December** and take up the opportunity to have your donation towards a vital new service for people with lymphoma **doubled**. Look out for reminders nearer the time.



Regular giving

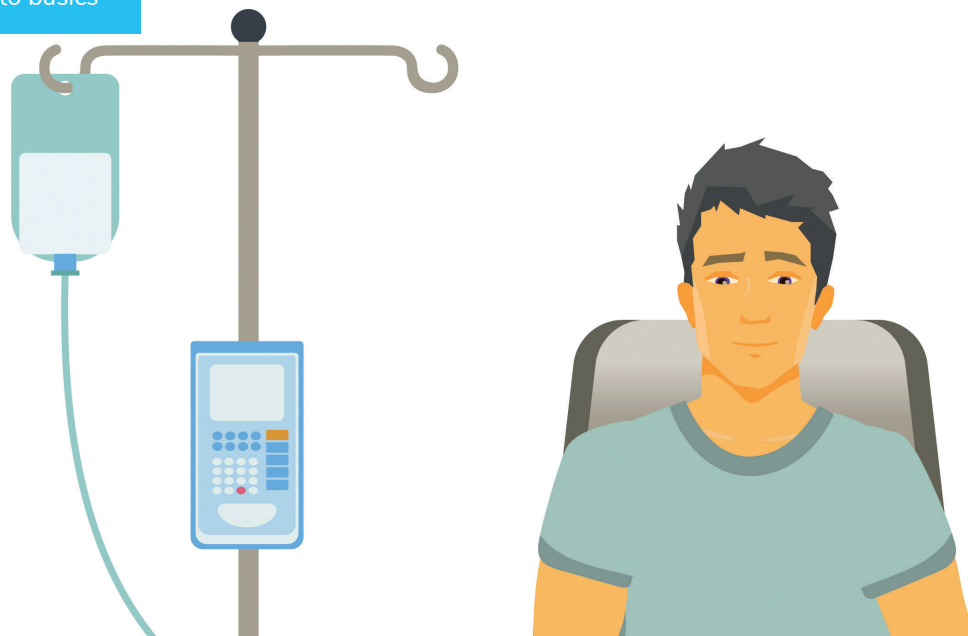
As we head towards Christmas, many of us are looking for ways to show we care. A meaningful way to show your support of Lymphoma Action's work is to start making a small regular gift, such as £6 a month. Regular gifts help us to plan better and could help us reach even more people affected by lymphoma throughout the year ahead. Call us on 01296 619400 or choose 'set up a regular gift' at lymphoma-action.or.uk/donate.

It's the little things...

Turn your loose change into something amazing by requesting one of our collection boxes, for your home or business. Maybe you could ask your local pub or shop to take one for us too? Pennies really do turn into something magic when they are collected for Lymphoma Action.

Email fundraising@lymphoma-action.org.uk to order yours today.





Spotlight on: CAR-T cell therapy

In August, Lymphoma Action hosted a webinar on CAR-T cell therapy, covering what it is, how it works and the process of having it.



We were joined by Consultant Haematologist Dr Cathy Burton (far left), Clinical Nurse Specialist for CAR-T Kathryn Riley (left), both from St James's University Hospital Leeds, and Fiona (page 18), an individual with lived experience of CAR-T cell therapy.

CAR-T stands for 'chimeric antigen receptor'

- C chimeric** it is made up of parts – the proteins involved are specific to each individual.
- A antigen** designed against the protein that sticks out of the cancer cell of the individual patient.
- R receptor** forms a receptor that recognises the individual antigen, allowing the cancer cells to be destroyed.
- T T-cell** the connection between the antigen and receptor on the T cell releases cytokines which can kill the cancer cell.

What is CAR-T cell therapy and how does it work?

CAR-T cell therapy is a type of immunotherapy. It uses T cells from your own immune system to fight lymphoma. It is a very personalised treatment for each individual patient and their specific cancer.

T cells are a type of white blood cell. T cells can recognise and kill 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.

In CAR-T cell therapy, your own T cells are collected and sent off to a lab. In the lab, they are engineered, or reprogrammed, so they can recognise and stick to a particular protein (antigen) on the surface of your lymphoma cells. These genetically modified T cells are known as 'CAR-T cells'.

These CAR-T cells are then grown in the lab, returned to the treatment centre and given back to you like a blood transfusion. When they stick to the lymphoma cells in your body, the CAR-T cells are activated to release cytokines which kill the lymphoma cells.

Who might have CAR-T cell therapy?

This type of treatment is used for some types of lymphoma that have either not responded to treatment or where the lymphoma has relapsed after standard treatment.

Currently CAR-T cell therapy is available for:

- diffuse large B-cell lymphoma that has relapsed after two previous therapies
- diffuse large B-cell lymphoma that is considered high-risk, and has not responded to treatment or has relapsed within a year
- primary mediastinal B-cell lymphoma that has relapsed after two previous therapies
- some low-grade lymphomas that at relapse have transformed to high-grade
- a specific type of follicular lymphoma known as Grade 3B
- mantle cell lymphoma that has relapsed after chemotherapy and treatment with a BTK inhibitor.

A national panel of experts is used to decide if you are eligible for CAR-T cell therapy following a referral from a specialist doctor.

CAR-T cell therapy can be an effective treatment option for some people. However, it is not suitable for everyone. 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. It is important to consider physical fitness, as well as psychological and social factors to ensure it is the right treatment choice for you. CAR-T cell therapy requires a stay in hospital so you can be closely monitored.

Having CAR-T cell therapy

CAR-T cell therapy involves a number of different steps.

1. Preparation

Before your treatment, you are invited to meet the CAR-T cell team at the hospital. This is an opportunity to discuss the treatment and ask any questions. You have a range of tests and are given advice on exercise, diet and other things you can do to prepare for your treatment.

2. Collecting your T cells

On the day of collection, a doctor or nurse puts a thin flexible tube into a vein in each of your arms (or will use your central line, if you have one fitted). These tubes are connected to a cell separator machine. Your blood passes through the machine which collects your T cells and returns the rest of your blood into your other arm. This process takes about 4 to 6 hours. You can go home afterwards, unless you are already staying in hospital.

3. Making the CAR-T cells

CAR-T cell treatments are made individually for each person. Your T cells are frozen and sent to a lab, usually in Europe. In the lab, your T cells are modified to recognise a protein on your lymphoma cells. They are then grown until there are enough of them to treat your lymphoma.

Making and growing the CAR-T cells can take 3 to 4 weeks. During this time, you might need chemotherapy or radiotherapy to keep your lymphoma under control. This is called 'bridging therapy'.

4. Chemotherapy

Once your CAR-T cells are ready they are sent back to the hospital where you are being treated. You will have checks and tests to ensure you are well enough to continue the treatment. 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 work more effectively. This is usually given as an outpatient over 3 days.

5. Having your CAR-T cells

To have your CAR-T cells, you are likely to stay in hospital the night before for final checks and tests. You will be given pre-medication, such as paracetamol and antihistamines, to help prevent any reactions. A single dose of CAR-T cells is given through a drip into a vein, or through a central line if you have one. It only takes a few minutes. This is known as 'day zero'.

6. Monitoring

You are monitored closely in hospital during and after the treatment. Most people stay in hospital for at least 14 days. After you leave hospital, you need to stay close by (usually within an hour's travel) for at least 4 weeks after having your CAR-T cells, in case you develop side effects.

If you live more than an hour away, you might need to arrange accommodation closer to the hospital for a few weeks. Your hospital team might be able to help you arrange this. 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.

7. Follow up

You have follow-up appointments with your CAR-T cell therapy team, every 3 months for the first year. You will also have regular appointments with your local haematology team. You may need regular tests and treatment for any ongoing side effects such as low blood counts. You will also be given advice on living well, including diet and exercise, and the likely need to repeat any past vaccinations.

What are the possible complications and side effects?

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

Cytokine release syndrome (CRS)

CRS happens when CAR-T cells are activated and release chemicals called cytokines. When lots of cytokines are released at once, they can overwhelm your body. Signs and symptoms of CRS include fever, low blood pressure and low oxygen levels in your body. CRS most commonly develops within 10 days of having your CAR-T cells. Most cases are mild and easily treated. However, severe or life-threatening reactions can occur. CRS usually gets better within a few days with treatment.

Neurotoxicity

When lots of CAR-T cells are activated they release chemicals that can affect your nervous system. This neurotoxicity can cause symptoms such as confusion, difficulty speaking or writing, headaches and tremors. Symptoms are usually mild and get better on their own in a week or two.

Occasionally, more serious symptoms such as seizures or life-threatening problems such as swelling of the brain can occur. Your medical team will monitor you closely so they can start treatment promptly if you need it. For example, you are asked a set of questions, including writing a sentence, twice a day so your team can look for changes.

Low blood counts

A combination of chemotherapy and CAR-T cell therapy often leads to low blood counts. You have blood tests to check your blood counts after you leave hospital. If your blood counts are very low or are causing problems, you might need blood transfusions or growth factors to help boost them.

Infections

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. This increases your risk of developing an infection. 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.

How successful is CAR-T cell therapy?

You will have a scan at day 28 and day 100 to see how your lymphoma has responded to treatment. Clinical trials and experiences so far show that approximately a third of those having CAR-T cell therapy get a long-term remission of their lymphoma.

Where is CAR-T cell therapy available?

CAR-T cell therapy can only be given at approved treatment centres that have the facilities and staff to administer it safely.

Initially only a few centres offered this treatment, but it is now more widespread across the UK (see list opposite, and it's likely that more centres will be offering the service in the future).

You may have to travel some distance to have this treatment but the hospital team can arrange accommodation.



- King's College Hospital
- University College London Hospital
- University Hospitals Bristol NHS Trust
- Queen Elizabeth Hospital Birmingham
- The Christie NHS Foundation Trust
- Manchester Royal Infirmary
- Newcastle Hospitals NHS Foundation Trust
- Cambridge University Hospitals NHS Foundation Trust
- Royal Marsden Hospital, London
- Leeds Teaching Hospitals NHS Trust
- Churchill Hospital Oxford
- University Hospital Southampton
- Sheffield Teaching Hospitals
- Hammersmith Hospital, London
- Queen Elizabeth University Hospital, Glasgow
- University Hospital of Wales.

Fiona's CAR-T story



Fiona was diagnosed with diffuse large B-cell lymphoma in 2007. She had treatment with chemotherapy and radiotherapy, but her lymphoma relapsed in 2019. Further treatment was unfortunately not successful and her medical team suggested CAR-T cell therapy, a very new treatment option at the time. She was assessed and successfully put forward to the national panel as a candidate for CAR-T cell therapy.

Watch videos of Fiona on our website where she talks through her experience of receiving CAR-T cell therapy: lymphoma-action.org.uk/CARTcells

Fiona explains how she felt during the treatment process, how closely she was monitored and treated for side-effects, and her emotions leaving hospital. She also highlights the importance of support and praises her medical team.

Remembering a loved one

We are enormously grateful to everyone who donates to Lymphoma Action in memory of a loved one. We know how difficult a bereavement can be and how special these gifts are.

Making a donation in memory is a touching way to honour the life of someone special, while at the same time funding much-needed information and support for everyone affected by lymphoma. This year we have received over £100,000 of incredible in memory donations from our wonderful supporters. Every gift, no matter the size, makes a difference.

There are a number of ways to remember your loved one, such as making a donation in their memory, setting up a personalised Tribute Space, holding a collection at a funeral, taking on a challenge, or hosting a memorial event.

“ Colin passed and I saw the in memory page and thought what a wonderful idea. I want anything I do to go to Lymphoma Action, to help another family, loved one or partner with information and support. Lymphoma Action and the Tribute Space page has been the best thing! Colin will always live in my heart.



Scott, set up a Tribute Space in memory of his partner, Colin, who passed away from lymphoma in 2022.

If you would like to discuss making a donation in memory of a loved one, please contact us on **01296 619400** or **fundraising@lymphoma-action.org.uk**. For more information visit our website: **lymphoma-action.org.uk/donate-memory**.



Ahilan's story

Ahilan was diagnosed with follicular lymphoma in 2020, after initially suspecting that he had a kidney stone.

I had very few symptoms leading up to my diagnosis of lymphoma in April 2020 at the age of 49. In retrospect, I was a lot more tired than usual for the six months or so beforehand but put that down to my job as a GP and the general 'busyness' of everyday life.

In February 2020, I felt a sharp pain in my left side which was strong enough to wake me from my sleep. It went away after a couple of hours, but this happened three nights in a row. I thought it best to see my GP, as I thought I might have a kidney stone.

I was sent for an X-ray, which came back as normal, but a week later the pain returned and kept me up all night.

My GP sent me to the emergency urology team, where they performed blood tests and a CT scan. My blood test results showed poor kidney function, and the scan showed possible kidney fibrosis that needed further investigation. An initial biopsy taken from the area was inconclusive, although I was told by my medical team that they suspected lymphoma. Meanwhile, I had a stent and nephrostomy bag fitted to prevent further kidney failure, as regular blood tests were showing that my kidney function was getting worse.

Around three weeks later, a further biopsy confirmed that I had follicular

lymphoma and that I would need to start treatment with chemotherapy. As someone who has always lived a healthy lifestyle it was quite a shock. I started the first of six sessions of R-CHOP chemotherapy in May 2020.

After my third session of chemotherapy, the nephrostomy bag fitted to prevent further kidney failure was removed. Just after this procedure, and while walking the dog with my wife Tracey, she noticed I was struggling. When we got back home I had a lie down and started shivering; my temperature was 39.5°C. I phoned my GP who told me to go to the hospital.

What I was experiencing was neutropenic sepsis and the next five days were a blur; all I can remember is throwing up on the floor and there was a lot of blood. I was in a haze and it wasn't until day five that I started to be aware of things again. In hospital I was given antibiotics for the sepsis and when I was able to go back home, I had a further week's worth of oral antibiotics to take.

Once I had recovered from sepsis, I continued my treatment and finished chemotherapy in August 2020. Thankfully, I received the news that I was in remission in October 2020.

I have struggled with a number of side effects such as fatigue and I can still tell that my energy levels haven't returned to what they were before my diagnosis. But for me the worst side effect has been chemo brain and even now I still don't feel the same as I was before treatment.

I returned to work within two weeks of finishing treatment, working just mornings. As a GP I don't feel I can manage the very long days at this stage.

We were able to buy a motor home, and regularly scoop up the dog and go away. We are enjoying the chance to do a lot of walking, although I have noticed that if I do a very long walk (around 8 to 10 miles) one day, then I can only do a short walk the next. Keeping active is important to me and I used to do two workouts a day; one cardiovascular and the other weights. I think being fit beforehand really helped me through my treatment and it is also having an impact on my recovery.

One of the really challenging aspects for me was that that my treatment took place during the COVID-19 lockdown. I had to go to every chemotherapy session on my own and when I had sepsis, my wife had to leave me at the door of A&E, which was frightening for us both.

In January 2023 a COVID-19 antibody test showed that I had full immunity to the virus and since then I have been doing a lot of living! It's been wonderful doing normal things like going to concerts, restaurants, pubs and the cinema. Tracey and I also took part in Lymphoma Action's Bridges of London walk earlier this year, which was fantastic! I now make the best of my time and enjoy living life.

As I am sure is the case with most people who have been through a cancer diagnosis, things crop up and I worry if the lymphoma has come back.

I never used to go to the doctor, but now I always get checked out if there is something I am not happy with, like a persistent cough or aches and pains.

Although I am reasonably well, I have been left with just one functioning kidney as I have stage three kidney disease following the removal of the stent in the kidney affected by the lymphoma. I was given the option to have another stent, but I have decided against it. The risk with this is that the kidney will eventually die, which is probably what is happening, and may be why I still get very tired – particularly by the afternoon.

I am still working, but very much on a part-time basis now and I have decided to bring my retirement forward by a few years and take a year out with Tracey.

Having our motorhome now, we are looking forward to packing up and travelling to wherever we fancy with our beloved dog.

“ Being diagnosed with lymphoma was something of a shock, but I was determined to meet it head-on. I feel I live in the shadow of the diagnosis, but that doesn't affect my enjoyment of life.

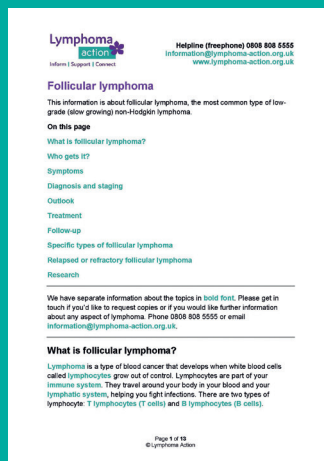


Updated information on follicular lymphoma

We have recently revised our information on follicular lymphoma. Read the latest version on our website or download a PDF at lymphoma-action.org.uk/FL

Our medical information – did you know?

Our medical information is evidence-based, approved by experts and reviewed by users every three years. Lymphoma Action writers work with professionals who have current knowledge, experience and expertise in the relevant field. Our information is also reviewed by lay people who consider whether it answers all the questions in a straightforward way. Our information is accredited to the Patient Information Forum (PIF) quality mark, which indicates we produce trustworthy health information.



✓	Evidence-based
✓	Approved by experts
✓	Reviewed by users

Bispecific antibodies



We asked Dr William Townsend, Consultant Haematologist at University College Hospital London (UCLH), about this new treatment. Dr Townsend leads a programme of early phase trials in lymphoma at the UCLH NIHR Clinical Research Facility. His work is supported by funding from the UCLH NIHR Biomedical Research Centre.

What are bispecific antibodies?

Bispecific antibodies are an exciting new class of immunotherapy drug that are showing promise in the treatment of a range of cancers.

The principle of bispecific antibodies is that they attach to two targets:

- one on the surface of cancer cells and
- one on the surface of cells of the patient's immune system (T-cells).

This means that cells of the immune system come into direct contact with the cancer cells, and this leads to activation of the T-cells which in turn kill the cancer cells.

How can bispecific antibodies be used to treat lymphoma?

A number of bispecific antibodies have been developed for the treatment of B-cell lymphomas. These target CD3 on T-cells and CD20 on the cancer cells. At present there is most evidence for their use in diffuse large B cell lymphoma (DLBCL) and follicular lymphoma but also emerging data in mantle cell lymphoma and some other lymphoma types. In the future it may be possible to use bispecific antibodies to treat other types of lymphoma using different targets.

Who can receive this treatment?

In the past, bispecific antibodies have only been available in the UK within clinical trials but more recently, two bispecific antibodies, epcoritamab and glofitamab, have been available via compassionate access schemes for patients with some types of relapsed B-cell non-Hodgkin lymphoma. Precise details of who has been eligible for these via compassionate access schemes varies and is dependent on the company that makes the drug assessing each case. In the last few weeks, NICE has given a positive recommendation for glofitamab for the treatment of relapsed or refractory DLBCL in patients who have had at least two prior lines of treatment. At time of going to print, glofitamab is awaiting a licence for this from the UK regulatory body (MHRA) but in the meantime is available via the MHRA Early Access to Medicines Scheme (EAMS).

Patients will need to undergo some standard tests to assess fitness and suitability for this treatment. Unfortunately for some patients with relapsed or refractory DLBCL they would be assessed as too unwell from the lymphoma or other health conditions to receive this treatment. Trials and assessments are ongoing for the use of bispecific antibodies in other lymphoma types, patients groups, and in combination with other drugs.

What evidence is there that this treatment works?

Evidence for how well these treatments work comes from international clinical trials. Evidence shows that about 40% of patients who received glofitamab for relapsed DLBCL after at least two lines of prior therapy had a very good response and achieved complete remission. For patients who achieved a complete remission, a high proportion remained in remission with no evidence of relapse 18 months after starting treatment. Similar results have been demonstrated with epcoritamab.

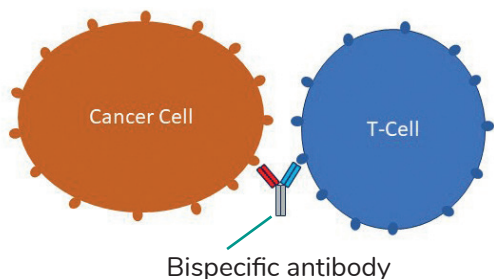
How are they administered?

Bispecific antibodies are administered much like other antibody-based therapy, such as rituximab. Some of the drugs are given as an infusion into a vein (intravenous infusion) over a few hours, and others are given as an injection under the skin (subcutaneous). To reduce the risk of side effects, the antibodies are usually started at a low dose and the dose is increased over a number of weeks (known as step-up dosing). Once at the target dose the drug is given every few weeks. There is typically a need to be admitted to hospital for initial dosing (number and duration of hospital admissions varies) but treatment can rapidly be moved to the outpatient setting in most cases.

What are the likely side effects?

Like all treatments there are potential side effects. Pre-medications including steroids are given to reduce the risk of side effects. The main side effects occur because the immune system can get 'over-stimulated' leading to a condition called 'Cytokine Release Syndrome' (CRS). CRS may take the form of a high temperature with no other features, or, if more severe, the high temperature can be accompanied by low blood pressure, fast heart rate, and low oxygen levels. This can be a very serious side effect. CRS is most common when the drugs are first started which is why initial dosing is performed as an inpatient and the dose is increased gradually. If severe CRS develops, treatments including steroids and tocilizumab may be given to treat it. It is rare to have to stop bispecific antibody therapy due to CRS.

Neurotoxicity, which is a relatively common and sometimes very severe side effect of other immunotherapy, is a rare side effect of bispecific antibody therapy. As with most treatments, there is an increased risk of infections with bispecific antibodies. Infections can be serious and may lead to a pause in treatment. Side effects that are typical of chemotherapy (hair loss, nausea and vomiting) are rare with bispecific antibody therapy and in my experience most people feel well while on treatment.



How bispecific antibodies work

1. Bispecific antibody binds cancer cell and T-cell simultaneously
2. Cancer cell and T-cell come in to close contact
3. T-cell is activated
4. T-cell releases chemicals that lead to death of cancer cell
5. Chemical signals lead to recruitment of more T-cells

How do bispecific antibodies and CAR-T cell therapy differ?

Both bispecific antibodies and CAR-T cell therapy aim to engage the immune system to fight the cancer. There are important similarities and differences.

For CAR-T cell therapy, cells have to be taken from the patient and be engineered in a lab before being infused, this process typically takes a few weeks. During this time 'bridging therapy' is usually needed to control the lymphoma. Unfortunately sometimes the lymphoma progresses during this time and patients are no longer fit enough to receive CAR-T. With bispecific antibodies there is no need for cell collection and manufacturing, and therefore treatment can be started sooner and bridging therapy is not usually required. It is sometimes referred to as an "off the shelf product".

CAR-T cell therapy requires a lengthy hospital admission in a CAR-treatment centre which may not be the patient's local hospital for treatment whereas I hope that bispecifics will be delivered in a broader range of hospitals so that people don't have to travel so far for treatment, and are usually only admitted to hospital for a few days during the step-up dosing.

Whilst some of the side effects are similar between the two treatment approaches, the risk of severe CRS is lower with bispecifics and neurotoxicity is rare. Bispecifics have to be given every few weeks (for up to 12 cycles of glofitamab or until progression with epcoritamab), whereas CAR-T cell therapy is a 'one-off' treatment.

We don't yet have enough data to know if the long term outcomes are equivalent between these treatment options, longer term follow up of the bispecific antibody trials will be important to judge this.

Whilst it is very exciting that we now have access to both of these highly active approaches for our patients with relapsed DLBCL, as clinicians and researchers in this field, we have a lot of work to do to find out how best to use these two powerful treatment options. Research continues to determine if some people are destined to do better with one approach than another, which order we should sequence these treatments in, and whether they can be combined with other treatments.



Our biggest Blood Cancer Awareness Month ever!



Danielle McLelland and her team

We asked you to help us #TalkLymphoma and you did not disappoint. Hundreds of you have helped us to raise awareness and vital funds – from John O’Groats to Lands End, from neighbourhood gatherings and family BBQs to corporate charity cricket matches and 100mph challenges! We are so grateful to every single one of you.

So whether you zipped, baked, golfed, ran, swam, trekked, walked, jumped, shared, donated and most importantly talked.....

Thank you!

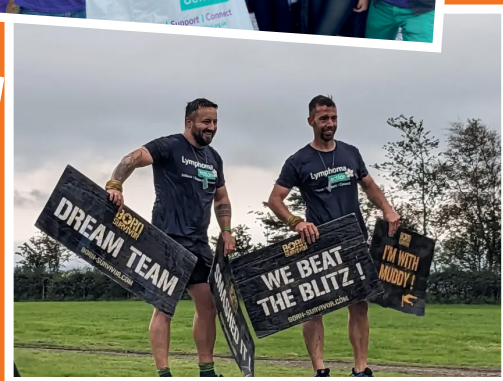


The team at Mark Holt & Co

BCAM 2023 in figures

More than 450 of you answered our call!
More than £90,000 was raised in September.
Over 40,000 people engaged with us on social media.





Thank you to **everyone** who helped raise money and awareness this BCAM, including Kirsty, Bridget and Derek, the Dent family, the zip wire challengers, Faye, Neil & Tony, Adam, Emily & Hannah, and Melinda & Milly.





Jamie's story

Jamie talks about his experience of diffuse large B-cell lymphoma

I had never had any health issues before my diagnosis of diffuse large B-cell lymphoma in February 2023. I was fit and healthy - going to the gym, playing squash and running 5K once a week. I had never smoked, and hardly drank alcohol. So it was a shock to be told I had blood cancer, but it just shows how it can happen to anyone.

I had been experiencing a range of symptoms since October 2022, including some of the more common symptoms of lymphoma such as wringing night sweats and fatigue. In addition, I was experiencing intermittent pain in my spleen, a continual cough and an inability to breathe which led to me constantly being sick. In addition, I had pain in my joints that would literally move from one area to another.

Some days I couldn't walk because of the pain in my knee, and then others it would be because of my ankle. In the end I was struggling to even walk the dog.

The route to finding out what was causing all my symptoms wasn't an easy one, and I actually received my lymphoma diagnosis while I was an inpatient in hospital. Over the course of a few months, I had numerous tests and scans including ultrasounds, CT scans, MRI scans and blood tests which all proved inconclusive. After many appointments, and spells in A&E, I was admitted to hospital where I stayed for three weeks before my diagnosis. During that time, I needed a chest drain, antibiotics, and various infusions. A scan of my spleen had spurred a referral to haematology and, following a PET scan and biopsy, I received the diagnosis of diffuse large B-cell lymphoma (DLBCL).

It might sound odd but my overwhelming feeling when I was given my diagnosis was of relief. I finally had an explanation of why I was feeling the way I did, and it meant that there was a way forward in treating my symptoms. Hopefully I would start to feel better for the first time in many months.

I began the first of six rounds of R-CHOP chemotherapy in March 2023 which were given in three week cycles. The first ten days of a chemo cycle were always tough. I had a few side effects, including sickness and an altered sense of taste. But I knew that the next ten days would be better as the side effects started to ease. All the while, I kept telling myself that 'this will pass', and I would concentrate on the next stage and counting down the markers leading to the end of my treatment. Despite the side effects, I was actually in a much better place compared with how I was feeling before my diagnosis.

I am on a couple of clinical trials for my lymphoma. I have taken part in a research study called DIRECT (DLBCL Interim Response Evaluation for Customised Therapy), trying to develop a new blood test using genetic analysis to help determine how well lymphomas respond to existing treatments. I also participated in the REMoDL-A trial which is a comparing standard R-CHOP with R-CHOP with the addition of a drug called acalabrutinib. I was in the arm that did not receive the additional drug. Being involved in these trials has meant that, amongst other things, I have received extra scans which I actually found quite helpful.

The scans meant that I could see how things were going as my treatment progressed. I will also be on additional monitoring for a few more months, which is another added reassurance. It has also been good to know that I am potentially helping other people in the future, who may receive a similar diagnosis.

Since completing treatment this August, I have been living a normal life as much as possible whilst being careful, keeping my distance in crowded places and just generally being a little bit more cautious. I took part in Lymphoma Action's Bridges of London walk two days after receiving chemotherapy, which was just wonderful. The information and support we received from the Charity throughout this journey has been invaluable, particularly for my wife as she felt she was given the tools she needed to cope, and an understanding of what to expect.

I have started exercising again and have continued work as a mortgage advisor. It's just so nice to be doing 'normal' things again. We are looking forward to a much-anticipated trip to Cape Verde towards the end of the year!

“The support and love from family and friends during this time has certainly helped me to face my diagnosis and treatment with optimism and positivity.”



We're investing in the future, thanks to you




At Lymphoma Action, we focus on delivering the best possible information and support to people affected by lymphoma. We are ambitious but considered in how we develop our services so that no one has to face lymphoma alone.

Thank you to all our wonderful supporters. With your help we are in the fortunate position of having additional reserves which we are investing in new activities. A particularly generous legacy received in 2021 has also been set aside for these to the end of 2025. Your continued support for core services, in addition to these new activities, is very much needed and appreciated:

- We are making our website more accessible and user-friendly, as it is our most important source of information.
- Our team is working on a new project to help people prepare for cancer treatment.
- We are developing a new education programme specifically for Clinical Nurse Specialists new to lymphoma.
- With a new Social Media Manager in post, we are planning more campaigns like 'let's talk lymphoma'.
- By recruiting two additional colleagues we can increase the number of people who can access our Helpline Services, Buddy Service, Online Support Groups and Closed Facebook Group.
- We continue to improve our services using better photography and iconography and seek feedback to see how we're doing.

Legacies and donations of all sizes mean we can support people affected by lymphoma better than ever before. Remembering Lymphoma Action in your Will is a wonderful way to continue supporting people with lymphoma beyond your lifetime and into the future. If you would like more information, or to request a leaflet, visit lymphoma-action.org.uk/legacy, contact Sarah on 01296 619407 or email s.knowles@lymphoma-action.org.uk



The Epstein-Barr virus is linked to several types of lymphoma

With thanks to Viracta Therapeutics, Inc. for writing this article.

Epstein-Barr virus (EBV) is a member of the herpes virus family and is one of the most common human viruses. Approximately 90 to 95% of adults throughout the world are infected with EBV. Most people become infected during childhood but may never know, due to having only mild symptoms or no symptoms at all.

The virus spreads from person to person through bodily fluids, particularly saliva. However, you can also get the virus by sharing personal items, such as tooth brushes or eating utensils, with someone who has an active EBV infection.

The most well-known EBV infection is mononucleosis or glandular fever. After you get an EBV infection, the virus becomes latent or inactive in your body. In very rare cases, under certain circumstances of immunosuppression, the virus can reactivate, and EBV-associated diseases may arise.

Interestingly, EBV was originally discovered through its association with Burkitt lymphoma, a rare but fast-growing cancer mostly found in children and young adults in Africa. The discovery began in 1961 when Denis Burkitt, an Irish surgeon, presented a newly discovered lymphoma during a lecture at Middlesex Hospital Medical School, attended by a medical virologist, Anthony Epstein. Epstein was fascinated by this new lymphoma and asked Burkitt for tumor samples to be sent to him.

He then began focusing on isolating the viral cause of Burkitt lymphoma. In 1964, Epstein and his colleagues, Yvonne Barr and Bert Achong, published their discovery of viral particles in lymphoblasts isolated from a patient with Burkitt lymphoma. This virus, EBV, became the first human cancer virus to be described, and its discovery paved the way for further research into viruses associated with cancer.

We now know mutations in cells infected with EBV can lead to cancerous changes and increase the risk of developing certain rare cancers like B, T and NK lymphomas as well as nasopharyngeal and gastric cancers. For example, 5-15% of all diffuse large B-cell lymphomas, 40-65% of all peripheral T-cell lymphoma, and 60-80% of all post-transplant lymphoproliferative disorders are associated with EBV. However, EBV-associated cancers are uncommon, and most people infected with EBV will not develop cancer. Overall, it's estimated that EBV infection contributes to about 2% of cancers worldwide.

Experts are still trying to identify the specific mutations and why EBV infections seem to cause them.

Targeted therapies are being developed to treat EBV-associated lymphomas. These include small molecule inhibitors, immunotherapy, and cell therapies.



Top Tips: talking about lymphoma

Sometimes it can be a challenge to talk about lymphoma, and it can be difficult to start a conversation with other people. This might be the case if you have lymphoma yourself, or if you are a friend, family member or close to someone with lymphoma.

We asked members of our Facebook group for their 'top tips' and suggestions for talking to others about lymphoma. Here is what they told us.

Thanks to everyone for sharing their tips.

Tips for talking to children and young people

- When we went to the hospital to visit, I would have a picnic on the grass outside and count the buses or make daisy chains; just simple things to associate the hospital visit with fun things too.
- We told our children that 'mummy had some bad cells that needed blasting' and drew a picture to explain it. They were 5 and 7 at the time. We explained to them that the medicine also blasted good cells so that was why I'd lose my hair. My drawings weren't entirely scientifically accurate but they did the job!
- We used story books to explain to our children about their cousin with lymphoma. We found this very helpful.
- When explaining to children be as honest as possible. Update them when things happen as this will give them a feeling of control. Reassure them when it's treatable. Explain any changes that they may see happening, so that they are prepared.
- I gave facts to my 12-year-old in a calm reassuring way. This also helped me feel calm and reassured.
- It's a bit of the process I felt I had control over. We told only the children (late teenagers) when my tests started, and no-one else until we had a firm diagnosis and treatment plan.

“ For our 3-year-old grandson when his dad was in hospital, we used positive language, such as ‘daddy is in hospital getting better’ rather than ‘daddy is poorly in hospital’. We also explained that he was having medicine and would be going back in for medicine. The book ‘The Hospital Dog’ was brilliant and my grandson knows it by heart now!



Tom has lymphoma is written and illustrated especially for parents and carers to read with their children (primary school-aged) to help them understand lymphoma and its treatment. Order a free copy from the Lymphoma Action shop at lymphoma-action.org.uk/Shop.

Tips for talking to adults

- Be honest and tell them about the journey you are about to go on and how they can help. I wrote a blog, everything from my diagnosis to finishing chemo. It felt like scratching an itch. And writing it down helped me explain it to others.
- Recognise that those with and without lymphoma have different fears, emotions and reactions and so they need different forms of support from one another.
- Tell people that it won't be easy and that you'll need support at times, even if it's just regular messages from family and friends who do not live nearby.
- I told people 'I'm still the same person, there will be adjustments required but don't let lymphoma define what you think of me'.
- I gave my lymphoma a name (I called it Derek) so whenever I talk about it with my friends and family, we refer to it as Derek rather than lymphoma or cancer. It kind of gives a 'face' to it (which also means you can swear at it when it messes up your plans), and I found it just made it easier to talk about it to others. And I just generally tried to stay positive about it.
- Don't be afraid of silence and don't try to fill it by talking. Silence can be when people are processing, and it's ok to cry.
- Telling people my lymphoma was treatable but not curable stopped people telling me that once treatment finished I could 'go back to normal'.
- Set up a 'group chat' so that you (or someone on your behalf) can update everybody at the same time (instead of having to repeat the same thing over and over again). It is also handy for providing useful links to reputable sources of information about your treatment, so that they can refer back to it whenever they need to.
- We used a WhatsApp/messenger with friends, and I was able to reconnect with people with whom I had lost contact.
- People find it hard to understand watch and wait (active monitoring). I said it's hard to get your head around, but lymphoma isn't like other cancers and it's better to save treatment for when it's needed as you don't want to use up options too soon for little benefit, although new treatments evolve all the time.

- I found it helpful to be clear about it. For example, explain that it is a blood cancer.
- For really close family who would feel devastated by the news, we made sure we had all the Lymphoma Action materials ready to give to them.
- We let people ask questions and answered with all the information we were given. We told everyone to stay off Google and pointed them to Lymphoma Action!
- I directed everyone to the Lymphoma Action website because with all the will in the world I got tired of talking about cancer and wanted people to have the best information.
- When people ask about my treatment I'm careful to say that although chemo does work for most people it didn't quite make the mark for me, and I had to have a very special kind of treatment - like a stem cell transplant but where my cells were genetically modified (aka CAR-T cell therapy). I say I am now in remission (my consultant's words), but I never say it's cured or gone. I am now living my life to the full!
- When it feels like you have a mountain to climb and it all just feels impossible, overwhelming and never ending, focus on achieving just 1% improvement in some way and in 100 days... you're 100% there!

This information comes from our Facebook community. This is not intended to be medical advice and is not a replacement for advice from your medical team.

If you have any Top Tips to share, email the magazine Editor at publications@lymphoma-action.org.uk or join our Closed Facebook Support Group at facebook.com/groups/LymphomaActionSupportUK

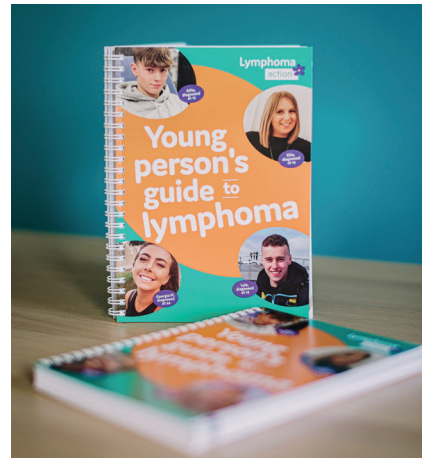
The 2023 edition of our Young person's guide to lymphoma is now available.

Lymphoma is the most common cancer in teenagers and young adults (15 to 24 years old), and every year in the UK, more than 500 teenagers and young people are diagnosed.

We've updated our Young person's guide to lymphoma which gives information about what lymphoma is, tests and scans and treatment.

It also answers some of the questions about day-to-day life, such as work or studies, alcohol, diet, exercise, travel and starting a family. The book includes quotes from young people who share their first-hand experiences.

The new edition of our Young person's guide to lymphoma is available to download from our website or order for free at lymphoma-action.org.uk/Shop.



Listen to our recent podcast



In our recent podcast Dallas Pounds, Lymphoma Action's Directors of Services and Lesley Carter, Age UK's Clinical Lead for Professionals and Practice, talk about 'having courageous conversations with your important people'.

Changes in life can happen very quickly, for example as a result of an accident or illness. So it's important for everyone to consider their wishes in the event they lose mental capacity or at the end of life.

Once you know your wishes, it is important to share them with those closest to you, so they know what to do if the worst happens. These conversations can be difficult and those around you may not want to talk about it. However, being courageous and having conversations can be empowering, letting you get on with life knowing those closest to you know your wishes.

“Conversations like this aren't easy, but taking practical steps and talking about your thoughts means that no one has to second guess your wishes. And you can put these wishes 'in a box' so that you can focus on living your life.

Listen to the podcast in full on our website [lymphoma-action.org.uk /Podcast#lesley](https://lymphoma-action.org.uk/Podcast#lesley)

Lymphoma Action services – here for you

Helpline Services: information and emotional support. Freephone **0808 808 5555**, Live Chat on the website (both 10am - 3pm, Mon - Fri) or email information@lymphoma-action.org.uk

Buddy Service: call the helpline to ask about being put in contact with a Buddy, someone who has been through a similar experience to you.

Closed Facebook Support Group: sign up at facebook.com/groups/LymphomaActionSupportUK

Webinars: hear about a range of topics. Find out what is coming up at lymphoma-action.org.uk/Events

Videos: on various topics about lymphoma. Find out more at lymphoma-action.org.uk

Lymphoma Voices: podcasts of personal experiences and medical opinion. Go to lymphoma-action.org.uk/LymphomaVoices

Live your Life: self-management workshops to help you improve your wellbeing after treatment or when on active monitoring. Find a workshop at lymphoma-action.org.uk/LYL

Online Support Meetings: meetings throughout the UK, including for family, friends and carers, and young people. Sign up at lymphoma-action.org.uk/online-support-meetings

Sunday 19 May 2024

Save the date for Bridges of London



Join #TeamLymphoma for this fabulous, family-friendly walk across London's most iconic bridges, taking in some of the Capital's greatest landmarks. The atmosphere last year was just incredible, and we can't wait to be there with you all again!

So grab your friends, family, colleagues and neighbours and experience the very best of London while making a huge difference to people affected by lymphoma.

If you can't reach London, you can still be part of #TeamLymphoma with your Bridges of Britain walk - your walk, your way, in your local area.

Find out more or sign up today at
lymphoma-action.org.uk/bridgeswalk

