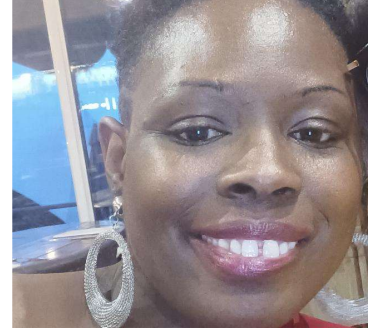


# lymphoma matters

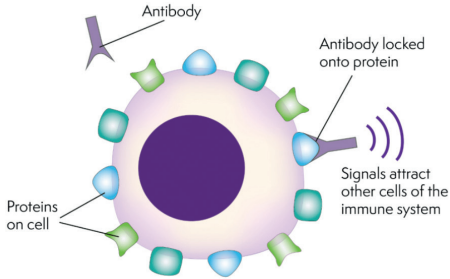
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for over 35 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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Editor: Anne Hook  
Cover: Emma and David who did a skydive for us – see page 18.

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To make a comment, to sign up, or to unsubscribe from the magazine, telephone 01296 619400 or email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk)

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

- Visit [lymphoma-action.org.uk/Donate](http://lymphoma-action.org.uk/Donate)
- Call us on 01296 619419

With thanks to Bristol Myers Squibb, Eli Lilly & Company, Incyte Biosciences Ltd 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 about our new range of Online Support Meetings (OSMs) on page 34.



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

## Connecting

Welcome to this year's first edition of *Lymphoma Matters*.

2022 was so rewarding as we invested in our policy and advocacy work, launched our new animations, focused on accessibility and received the Patient Information Forum accreditation (PIF TICK), which recognises the robust way we produce our information.

Our education and training programme for healthcare professionals also continued to grow and we saw over 470 doctors attend our Lymphoma Management Course for specialist registrars. These were just a few of the activities which your donations helped us to achieve.

Everything we do as part of our strategy (you can read our strategy at: [lymphoma-action.org.uk/about-us](https://lymphoma-action.org.uk/about-us)) is driven by the specific experiences and concerns of people affected by lymphoma. This includes the insights we received through the Lymphoma Coalition Patient Survey which you can read more about on pages 24-25. Our plans for 2023 are equally exciting with the launch of our new suite of Online Support Meetings (see page 34), our plans to expand our education for healthcare professionals and development of our information and peer support services. All of this has been possible because of the generosity of our lymphoma community.

Talking of community, I'm particularly looking forward to the return of a face-to-face National Conference in London on 13 May (see back cover), the theme of which is 'Connecting', after what has been a difficult few years of not being able to see or meet each other. And if any of you would like to make a weekend of it, our flagship and amazing Bridges event takes place the day after, although there are many other ways to show your support in 2023.

We look forward to seeing you in London or virtually at a webinar or an Online Support Meeting soon.

**Ropinder Gill**  
Chief Executive

## Lymphoma Action welcomes new Director of Fundraising and Communications



Our new Director of Fundraising and Communications, Deborah Laing, joined us in January following the retirement of our previous director, Karen Rabjohn. Deborah joins us from the sight loss sector, having headed up the fundraising team at Retina UK for the past six years. Prior to that, Deborah worked in the hospice world, gaining experience in a wide range of different fundraising disciplines. Deborah told us how excited she is to join the team: 'I am thrilled to be joining Lymphoma Action at such an important time in the charity's development. I'm looking forward to working with my amazing colleagues to ensure we reach and support as many people affected by lymphoma as possible.'

## Sign a petition calling on the Government to fulfil their cancer strategy

**One Cancer Voice (OCV) is a network of over 60 cancer charities, representing millions of people living with cancer. Together, we are calling for the UK Government to tackle the crisis in cancer care.**

A year ago, on World Cancer Day on 4 February 2022, the Government declared a 'war on cancer' and committed to tackling this challenge through the publication of a 10-Year Cancer Plan for England. Over 5,000 people, including many people with cancer and their loved ones, shared their experiences, needs and suggestions for what this plan should do. The government recently announced the publication of an interim 5-year 'Major Conditions Strategy', to replace the promised 10-Year Cancer Plan. We are devastated to have gone from anticipating a detailed, 10-year strategy dedicated wholly to transforming us into a 'world-leading' force in cancer care, to one part in a strategy spanning a huge range of conditions. Together, we are calling for the UK Government to put the needs of people with cancer first by:

- ensuring the upcoming Major Conditions Strategy is ambitious, fully-funded and listens to the voices and evidence of the cancer community and
- to commit to a longer-term strategy for cancer which focuses on transforming cancer research, diagnosis, treatment and patient experience.

**Please support us and sign the petition today via: [lymphoma-action.org.uk/one-cancer-voice-petition](https://lymphoma-action.org.uk/one-cancer-voice-petition)**

## Updates from NICE

We are pleased to report two important updates from the National Institute for Health and Care Excellence (NICE).

**NICE**  
National Institute for  
Health and Care Excellence

### NICE recommends axicabtagene ciloleucel for DLBCL and primary mediastinal large B-cell lymphoma

NICE has recommended axicabtagene ciloleucel as an option for treating relapsed or refractory diffuse large B-cell lymphoma (DLBCL) or primary mediastinal large B-cell lymphoma in adults after 2 or more systemic (whole body) therapies.

Axicabtagene ciloleucel is a type of treatment known as 'CAR T-cell therapy'. This treatment uses your own immune system to try to destroy lymphoma cells. Your body produces a type of lymphocyte (white blood cell), called a T cell, to fight infections and diseases, including lymphoma. Axicabtagene ciloleucel is made from your own T cells.

### NICE recommends polatuzumab vedotin for DLBCL

NICE has recommend polatuzumab vedotin with rituximab, cyclophosphamide, doxorubicin and prednisolone (R-CHP) for untreated diffuse large B-cell lymphoma (DLBCL) in adults, if they have an International Prognostic Index (IPI) score of 2 to 5. (IPI is a clinical tool developed to aid in predicting the likely outcome of treatment).

Polatuzumab vedotin is a type of treatment called an 'antibody–drug conjugate'. This is a strong anti-cancer drug joined to an antibody that binds to a protein called CD79b on the surface of B cells (the cells that are abnormal in DLBCL). This carries the drug directly to the B cells and kills them.

These drugs will be available for routine use on the NHS for the indications specified.

## Lymphoma Action Summer Prize Draw



Thank you to everyone who participated in our Summer 2022 prize draw.

The list of winners is available on our website at: [lymphoma-action.org.uk/summerprize-draw](https://lymphoma-action.org.uk/summerprize-draw)



## Communicating with your healthcare team

**If you have lymphoma, you are likely to communicate with many different healthcare professionals about your symptoms, diagnosis, treatment, ongoing management, and lifestyle. This can involve many different people, from your GP to nurses, consultants, and a range of other healthcare professionals during each stage of your lymphoma experience.**



**In December, Lymphoma Action hosted a webinar where Dr Wendy Osborne, Consultant Haematologist at Newcastle upon Tyne Hospitals NHS Foundation Trust, spoke about ways to get the most out of conversations with your healthcare team.**

**Wendy was joined by Lesley and Mike, who are both living with lymphoma and who shared their experiences and views on this topic.**

This article is a summary of some of the key points from that webinar.

## Preparing for a conversation with your specialist

Appointments with your lymphoma specialist are likely to include a lot of information.

You might like to spend a bit of time thinking about it beforehand so you are prepared to get the best out of the conversation.

- Prepare a list of questions you want to ask.
- Put your questions in order of importance to you. If time is running short, you don't want to run out of time to ask the question you consider most important.
- Take someone with you if possible and explain to them beforehand what you want to cover. They can prompt you if you forget to ask a question.
- Write down important points or ask the person with you to do this. Alternatively you could ask your medic if they would be happy for you to record the conversation.
- Having someone with you means you can talk through the appointment; having lots of information all at once can make it difficult to recall everything in detail.

## What makes a meeting go well?

Dr Osborne explained that the most important thing is for healthcare professionals to communicate clearly to people. If there is anything you don't understand, she would urge you to ask for more explanation.

She also urges people to get back in contact, often with the clinical nurse specialist (CNS), if other things come to mind after the appointment. People often ask additional questions about their treatment or about why they have been put on active monitoring (watch and wait).

Some people want to know absolutely everything from the outset, while others only want to hear what is necessary at a particular time. For example, some families might want to know about statistics.

However, statistics are often unhelpful as they don't take individual factors into account. Don't be afraid to tell your family and your healthcare team what you do – or do not – want to know.

If you are attending an appointment and your family has come to support you, then Dr Osborne commented that she would welcome them into the appointment, so long as the person with lymphoma is happy for this. That way everyone gets the same information at the same time. It also avoids having to repeat it and the risk of missing important elements. There are more people to remind you if you have forgotten something too.

## Talking to your medical team about worrying symptoms

If you feel something is not right with your body, it's important to have that conversation openly. Point out if things are getting worse, as symptoms of lymphoma do not come and go. If things don't improve, don't be afraid to get back in touch.

**If you have a temperature, or signs of infection call immediately – even if it is in the middle of the night. Prompt medical attention can prevent issues from becoming more serious.**

## I don't feel I should bother my doctor, they are so busy.

Often people feel their questions aren't important enough to raise or they might feel put off asking questions if appointments are running late. As Dr Osborne says, your medical team should be accessible and open to questions. She emphasised that it is not a bother and it is important to communicate any questions or concerns.

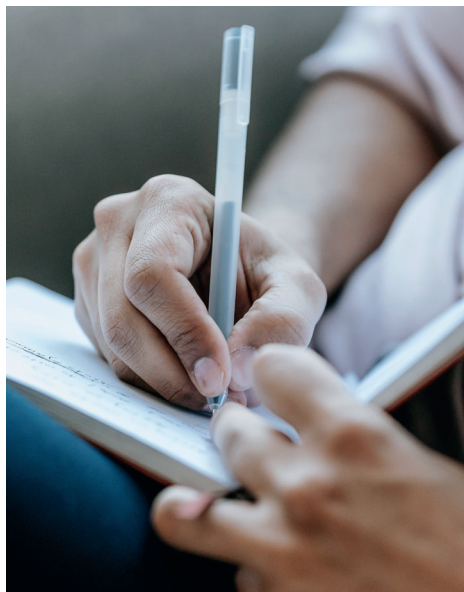
If you have a number of minor questions that aren't troubling you, and the surgery is running late, explain you have a list of questions and ask whether you can ask them now or whether you should raise them at the next meeting or over the phone.

## Your Clinical Nurse Specialist (CNS) is a valuable resource

For most people with lymphoma, your CNS is your first point of contact. The fact that there is someone you can contact is very reassuring. If you feel something is wrong, have the confidence to pick up the phone or send a message and say that you don't think things are quite right.

## When should I contact my lymphoma team and when should I contact my GP?

It will depend on what the problem is and whether you are going through treatment or are post-treatment.



Writing a list of questions to ask at your appointment helps to focus on what you want to cover.

For any lymphoma-related problem, it is best to contact your consultant or CNS. However, if you are struggling with something not related to your lymphoma then your GP might be better equipped to support you. For example, if you think you can feel a swollen lump, talk to your consultant or CNS. However, if you are experiencing signs of depression, you could talk to your GP.

## I am being offered video appointments, but would prefer to go into clinic. Can I request this?

Hospitals have opened up much more now and most doctors offer appointments either via telephone, video call or face-to-face. It is usually a good sign if your doctor suggests a telephone appointment as it is often an indicator that they don't have particular concerns.

Some people are keen to have virtual appointments to avoid any risk of infection and to save the challenge of parking. Others prefer to be seen in person.

If you have a preference – ask. They might not know what you would prefer. You may be able to work out with your team the optimal way forward, such as attending every other consultation in person.

You can view the webinar this article summarises at:

[lymphoma-action.org.uk/Communicating](https://lymphoma-action.org.uk/Communicating)

The Lymphoma Action website has a list of questions to ask your medical team. You may find this a useful starting point. Find the list at [lymphoma-action.org.uk/Questions](https://lymphoma-action.org.uk/Questions)



# Join our team of community volunteers

With the help of our wonderful volunteers, we aim to raise awareness of lymphoma and our services in communities across the UK to inform, support and connect people affected.



*'It was both a privilege and a pleasure to deliver a talk about my own lymphoma experience that I know touched their hearts and helped them better understand lymphoma.'*

## What's involved?

You can get involved with a range of online and face-to-face activities. From putting up posters, giving presentations, attending events or fundraising to anything you'd like to try!

*'Volunteering can give you a sense of purpose and something you will enjoy doing. You also make a real difference to the lymphoma community.'*

It's a flexible role where you choose a level of involvement that suits you from occasional support to organising your own activities, all with support from us! Your time will make all the difference to the success of our community activities and helping others understand lymphoma.

Find out more and register your interest at [lymphoma-action.org.uk/community-volunteer](https://lymphoma-action.org.uk/community-volunteer)

# Get involved in 2023

There are so many ways to raise awareness and show your support. Here is some inspiration to get you started, or you can come up with your own fundraising ideas!

## Celebration time!

Last year, almost 200 of you chose to raise money for your birthdays, weddings and anniversaries to help others affected by lymphoma.

Together, you raised a whopping £35,337 for Lymphoma Action. That's enough to cover the costs of getting our information to 9,789 people who received a life-changing diagnosis of lymphoma.

We are hugely grateful to you all for showing your support in such a wonderful way. Thank you so much.



If you have a celebration coming up that you'd like to use as an opportunity to donate to us in 2023, we would love your help. Find out how to get involved on our website [lymphoma-action.org.uk/celebration](https://lymphoma-action.org.uk/celebration) or contact the fundraising team by email at [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk) or call **01296 619400**.

## Join our Big Hair Dare bunch!



Taking on a Big Hair Dare challenge is a brilliant way to show your support for people affected by lymphoma. You can do it anytime, anywhere and do anything you dare to your hair.

Whether you fancy lopping your locks, getting the colours of the Lymphoma Action rainbow, or going the whole hog and braving a headshave, we'd love to hear from you.

You can grab your fundraising pack through our website at [lymphoma-action.org.uk/BigHairDare](https://lymphoma-action.org.uk/BigHairDare), or give us a call on **01296 619400**.



## Walk the Bridges of London with us on Sunday 14 May

Our Bridges of London Walk is a brilliant day out for all the family and a unique way to raise awareness of lymphoma, as well as money to help support all those affected.

The route crosses the River Thames via 10 of London's most iconic bridges and takes you past some of London's biggest and best landmarks.

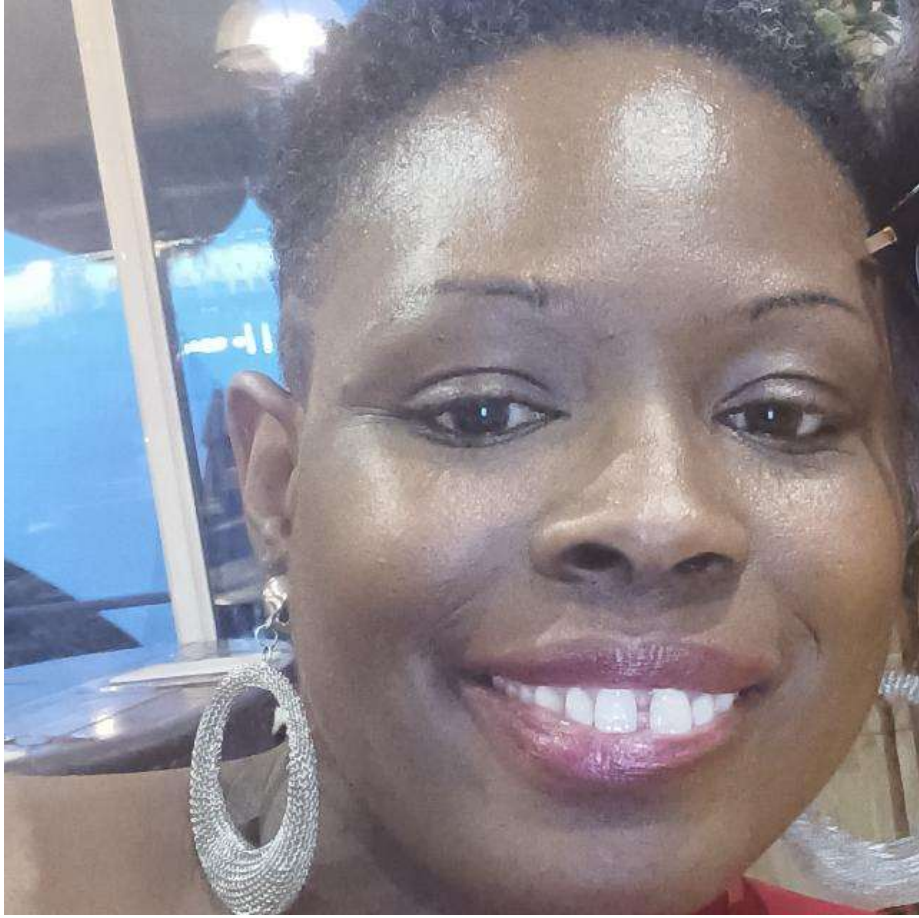
It's a completely flexible challenge you can take at your own pace, whether you choose to power walk the 7 miles, take a leisurely stroll, or stop for lunch along the way.

If you can't make it into London, why not take on our Bridges of Britain Walk instead, which you can do whenever and wherever you would like to. The only requirement is to cross at least one bridge on your route!

We're hoping to make 2023 our biggest Bridges walk yet and create a sea of purple to raise awareness of lymphoma.

Find out more and sign up at [lymphoma-action.org.uk/Bridges23](https://lymphoma-action.org.uk/Bridges23)





# A diagnosis of lymphoma has brought out all sorts of emotions

## Cornita shares her experience of low-grade non-Hodgkin lymphoma

At the beginning of 2021 I noticed a lump in my neck. It was tiny, but I felt sure it was growing. I was 42 and have been a massage therapist for over 26 years. In my job I have seen lots of lumps and bumps over the years and often they are fatty lumps or are raised lymph nodes because of an infection.

I phoned my doctor and talked through my concerns, but came away feeling reassured there was nothing to worry about.

But my mum and sister said they could notice a lump on my neck and urged me to get back in touch with the doctor.

I was referred to a cancer unit, as I had an ongoing lump that needed investigation. Blood tests were taken, and I was told the results looked fine, so I carried on and forgot about it. However, a little while later I got a phone call asking me to go back to the hospital as they wanted to take a biopsy.

This was carried out as a small operation. I didn't hear anything more for over three weeks.

I then received a phone call saying the results were back and could I come to the hospital. My sister insisted on coming with me and waited in the lobby while I went in. There were four doctors and a nurse there and they spoke very plainly about what the biopsy had revealed. I was diagnosed with lymphoma, a type of cancer.

I don't recall taking anything else in at that moment. All I could think about was 'How long will I live?' and 'What about my daughter?'

The nurse took me into a private room with my sister and I told her I hadn't even heard of lymphoma. She explained more about it, but in truth a lot of it didn't sink in at the time.

I needed to have a PET scan to identify where the lymphoma was and they explained to me that there was a small amount in my groin with more lymphoma in my neck.

At this point, the option of active monitoring (watch and wait) was discussed with me. In the media, whenever cancer is mentioned, it seems to me that the emphasis is on early diagnosis and treatment. The suggestion that I hold off treatment seemed to go against everything I thought about cancer.

As it turned out, I needed to start treatment so I decided to get my body as fit as possible beforehand. I detoxed for 4 weeks, cutting out meat and alcohol. I spent much more time watching nature with my sister and did more exercise; I even had a personal trainer!

I had R-CVP chemotherapy (rituximab plus cyclophosphamide, vincristine and prednisolone) and found it didn't affect me as much as I'd thought it would.

The treatment needed to be adjusted, as I started to experience peripheral neuropathy: a strange tingling, particularly in my hands.

A PET scan at the end of treatment showed I was now in remission, although I feel I'm not yet out of the woods.

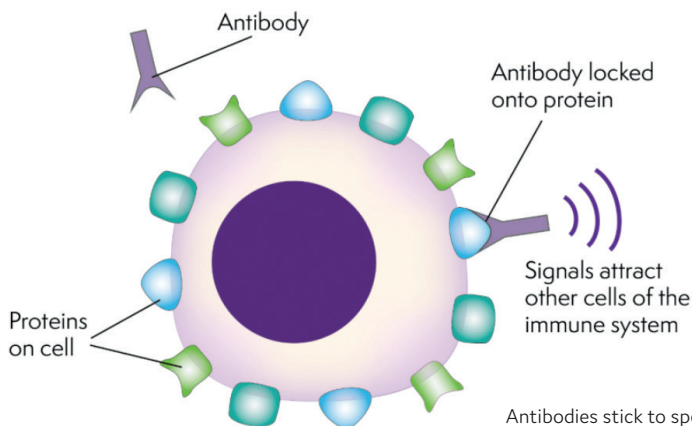
My daughter has been enormously supportive and is very happy I am in remission, although she does worry a lot that the lymphoma will come back. When I was first diagnosed, some of the children at school teased her, which may explain why she doesn't want to talk about it much and tends to hold her emotions in.

### *My experience of lymphoma has brought all sorts of emotions out in me.*

I feel passionately that people should know more about lymphoma and I want to support others who are going through a similar experience to me. That is why I have found the Lymphoma Action Closed Facebook Group so valuable. It feels such a safe, warm and friendly environment where people can talk about their worries or concerns, pose questions, discuss topics and share triumphs. It really has helped me get through this experience.

It's taken me quite a time to recover, and because the job I do is pretty physical, I want to avoid putting too much stress on my body for as long as I can. I have my own business and am fortunate that my two colleagues have been able to keep everything going while I've been away. I'm just planning to return to two days a week, albeit rather cautiously.

I feel strangely lucky that my lymphoma presented with a lump in my neck, otherwise I think I would have ignored some of the other signs that something was wrong. I would urge anyone who suspects there may be something wrong with their body, not to ignore it.



## Spotlight on: Rituximab

**Rituximab is commonly used to treat some types of lymphoma, but what is it and why is it used?**

### What is rituximab?

Rituximab is a type of targeted treatment called antibody therapy.

Antibodies are proteins made by your white blood cells. They help fight infections by sticking to proteins on the surface of cells that don't belong in your body. Once they have stuck to these proteins, the antibodies either kill the cell directly or help other parts of your immune system find and destroy the cell.

Antibody therapy uses antibodies that have been engineered in a lab to recognise and stick to a protein on cancer cells. This activates your immune system to destroy the cancer cell. Antibody therapy is also known as immunotherapy because it works using your own immune system. Rituximab targets a protein called CD20. CD20 is found on white blood cells called B lymphocytes (B cells). CD20 is found on both normal

B-cells as well as the abnormal B-cells that occur in many types of lymphoma.

Rituximab attaches to this CD20 protein and works in two ways, by:

- directly triggering cell death, and
- stimulating your own immune system to destroy the cell using a number of different mechanisms.

Rituximab is used to treat B-cell non-Hodgkin lymphomas and chronic lymphocytic leukaemia (CLL).

### How does rituximab differ from chemotherapy?

Chemotherapy is the administration of cytotoxic (toxic to cells) drugs to destroy cancer cells. There are many different types of chemotherapy medicine, but they all work in a similar way – they stop cancer cells growing and dividing.

Chemotherapy therefore kills cancer cells directly whereas immunotherapy such as rituximab acts by activating your own immune system.

This different mechanism of action influences the speed and duration of impact as well as potential side-effects of treatment.

Rituximab can be used alone or in combination with chemotherapy (often referred to as chemoimmunotherapy). In addition to their separate effects on cancer cells, there is evidence of a synergistic relationship between rituximab and chemotherapy. This means that treatment with rituximab may make cells more sensitive to chemotherapy, increasing the impact of treatment.

### What is the impact of rituximab on lymphoma care?

The availability of rituximab has made a big difference in the treatment of lymphoma. Patients have benefitted from improved outcomes, such as increased response rates and prolonged survival. By activating the body's immune system to specifically target cancer cells, rituximab avoids many of the potential damaging side effects of

many conventional chemotherapeutics. Rituximab therefore also provides an additional treatment option for those not able to have chemotherapy.





With some types of lymphoma, rituximab may also be used as a maintenance therapy. This is a long-term treatment plan, given after a successful initial course of treatment, with the aim of extending a period of remission and delaying the need for additional treatment.

Rituximab has therefore become a standard component of care for many types of lymphoma.

*'Rituximab has been a real game changer in the management of B-cell lymphomas. It significantly improves the effectiveness of chemotherapy resulting in improved outcomes for patients and better survival. In the main, it does not result in any significant additional side effects.'*

*Professor Andy Davies*

### Comparison of rituximab and chemotherapy

	Chemotherapy	Rituximab
<b>How they work</b> 	Directly kills cancer cells. Targets rapidly dividing cells.	Activates immune system. Targets cells with the specific protein.
<b>Speed</b> 	Can be quick to shrink tumours.	May take longer to see effects.
<b>Duration</b> 	Effects last whilst drug is in the body.	Can provide longer-term protection.
<b>Side effects</b> 	Can affect other rapidly dividing cells in the body. Examples: hair loss, nausea.	Can cause side effects as immune cells are activated. Examples: rash, inflammation.

## Rituximab - did you know?

Rituximab was the world's first antibody therapy approved for use as a cancer treatment. It was first approved in the US by the Food and Drug Administration in 1997 and in Europe by the European Medicines Agency in June 1998.

You may hear rituximab referred to as a **monoclonal** antibody. Monoclonal means that the antibodies are exactly the same, so they stick to exactly the same protein. You may also hear it referred to by the drug's brand name, MabThera®. A number of biosimilars are also available – such as Rixathon®, Rixience® and Truxima® – these are manufactured by different pharmaceutical companies, but all contain rituximab as the active ingredient.

A **biosimilar** is a copy of the original drug. Biosimilars undergo strict testing to check they work just as well as the original drug.

The **development of rituximab** has paved the way for other targeted treatments. For example the research and development of:

- other anti-CD20 monoclonal antibodies, such as ofatumumab and obinutuzumab
- monoclonal antibodies targeting other proteins on the surface of cancer cells
- bispecific antibodies that can bind to two different proteins to engage the immune system's T-cells.

**With thanks to Professor Andy Davies, Consultant Haematologist, University Hospital Southampton, for reviewing this information. For more about rituximab, visit: [lymphoma-action.org.uk/Rituximab](https://lymphoma-action.org.uk/Rituximab)**

## Lymphoma Voices podcasts

**Why not give our podcasts a listen as they offer lively and informative conversation around lymphoma topics? We are regularly recording more in the series, so check out [lymphoma-action.org.uk/LymphomaVoices](https://lymphoma-action.org.uk/LymphomaVoices)**



Here are just a few of our recently released podcasts.

**Living on countdown:** Lou, diagnosed with follicular lymphoma, talks about the challenges of living with a low-grade non-Hodgkin lymphoma and the impact on her mental health.

**Talking about stem cell transplants:** Healthcare professionals John and Angela discuss autologous and allogeneic stem cell transplants in the treatment of lymphoma.

**Two perspectives, one lymphoma:** Lyle, diagnosed with Hodgkin lymphoma at the age of 19 together with his mum Julie, comment on their shared experience of lymphoma.

**The role of the radiologist:** Manil Subesinghe talks about this role in lymphoma management.

**This version of me:** 28-year old Nia, who moved to the UK from the USA, discusses her diagnosis of Hodgkin lymphoma and how healthcare differs across the continents.

**My experience of a clinical trial:** Katie talks about her experience of receiving treatment for Waldenström's macroglobulinaemia through a clinical trial.

**Understanding relapse:** Advanced Nurse Practitioner Charlotte Bloodworth explains what relapsing in lymphoma means and strategies for treating.





## We are delighted to offer a free online Will-writing service through Bequeathed, to help you make your 'Will for Good'.

Having an up-to-date Will is the only way to make sure the people and causes you care about are looked after beyond your lifetime. The Bequeathed service offers all of our supporters over the age of 18 a free\*, fully advised Will from an accredited legal professional.

Whatever the size of your gift, your legacy will ensure that we continue to be there to help people to live with and beyond lymphoma.

### Write your 'Will for Good' in three simple steps

- Step 1:** Go to [lymphoma-action.org.uk/FreeWill](https://lymphoma-action.org.uk/FreeWill) where you will be directed to the Bequeathed website to complete an online interview. The questions asked help to gather all the information required to make your Will quickly. It takes around 20 minutes and there's online help at hand if you need it.
- Step 2:** Once you've completed the online interview, Bequeathed will arrange a 30-minute appointment with a legal firm. You can choose between a phone or video call. The firm will discuss your situation and your wishes and confirm that your Will fully caters to your needs.
- Step 3:** After your appointment, the legal firm will send you your free Will. Just sign it in front of witnesses and return to the firm. They will check it has been executed correctly and securely store it for you, also at no cost.

To sign up please visit [lymphoma-action.org.uk/FreeWill](https://lymphoma-action.org.uk/FreeWill)

If you have decided to leave a gift in your Will or would like more information about our free Will service, please email [legacies@lymphoma-action.org.uk](mailto:legacies@lymphoma-action.org.uk) or ring **01296 619400**.

\*Bequeathed donates up to 30 minutes of their expertise to help you make your free Will. For most people, that will be all they need. If you need additional advice, they'll provide you with a quote, and it's up to you whether to accept.

**bequeathed**   
make your Will For Good



# JUMP into June!

If you want to tick a parachute jump off your bucket list, now is your chance!

We're looking for volunteers to jump for Lymphoma Action this June - are you ready for the challenge? Flying through the clouds over 10,000 feet high and at 120mph is a truly unforgettable experience.

*'I will never forget that feeling of jumping from a plane. Dad and I both agree that it was an amazing experience.'*

Your parachute and fundraising pack are waiting for you. Jump in at [lymphoma-action.org.uk/Skydive](https://lymphoma-action.org.uk/Skydive) to take part in one of our special Skydive Days at an airfield near you.





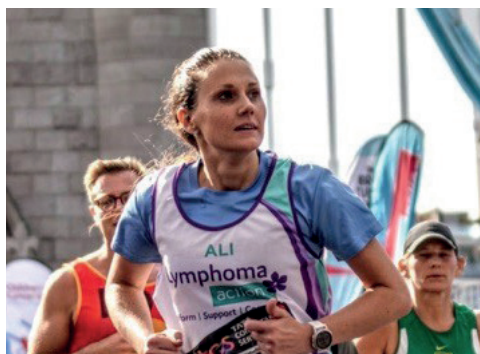
# Run for us

At the time of creating this magazine, our team of London Marathon runners are ramping up their training and boosting their fundraising with just weeks until they hit the starting line.

The race itself is really just the lap of honour following an incredible journey of teamwork and self-discovery for our amazing team of runners. We are so proud of them and all that they achieve for themselves and for Lymphoma Action.

We are now opening our waiting list for the 2024 London Marathon and this is your moment! Whether you're just starting out or have plenty of experience behind you, we are here to support you on this challenge of a lifetime. Get in touch today and make 2024 extra special!

Grab your place and see other running events we are joining this year: [lymphoma-action.org.uk/Run](https://lymphoma-action.org.uk/Run)





## My motto is 'health is wealth'

### Maddie shares her experience of Hodgkin lymphoma.

At the beginning of 2022, I was getting on with my life as a teacher, living and working in London. I was 30 and hadn't ever had any health issues.

In March 2022, I noticed a number of things that were worrying me health-wise. At the time they seemed fairly random and at first I didn't think they were connected. I had developed a lump at the side of my neck that felt about the size of a Malteser. It wasn't painful, but it wouldn't go away.

In addition, I had a really bad, chesty cough that wouldn't go away and I was struggling with breathing. The strangest symptom was the pain I was experiencing very shortly after drinking any alcohol.

I went to visit my GP and mentioned the cough and the breathing in particular. He thought I might have developed asthma and prescribed me antibiotics, but suggested I return if nothing improved.

The antibiotics didn't help. The symptoms seemed to be getting worse, particularly the alcohol-related pain which was now so bad that I had stopped drinking and socialising. I went back to the GP.

My GP organised for me to have blood tests, which indicated I had a really high Erythrocyte Sedimentation Rate (ESR) which is an indicator of inflammation. As a result, a chest X-ray and CT scan were arranged which showed there was something in my chest. In addition, I had a PET/CT scan and a biopsy of my neck.

A few days later, I was teaching at school and I received a phone call. I was told I had stage two Hodgkin lymphoma in my chest and neck. I just walked out of the school in shock. I felt devastated and terrified.

You hear about people getting cancer and wonder how you would feel if it was you. But nothing prepares you for what it's like.

At first I started questioning why I had lymphoma. Was it my fault? Have I done something to cause this? Have I not treated my body well? Having read more about it, I understand that there is no clear cause of Hodgkin lymphoma and that it isn't because of anything I have or haven't done.

The other strange reaction I had to the diagnosis was embarrassment. I was dealing with something that no one else around me was having to cope with and I felt awkward speaking about it.

***'In truth, I also felt some relief that there was an answer to these strange symptoms that were just not going away.'***

It wasn't just in my head and at least I now knew the cause of the symptoms and that, hopefully, with treatment things could improve.

I was told I'd have five cycles of ABVD chemotherapy (Adriamycin, bleomycin, vinblastine and dacarbazine).

Before treatment started, I was referred to a fertility specialist who told me I had the option to freeze my eggs if I wanted to, but it would take six weeks to do this and would delay starting treatment.



I talked it through with my doctor who explained that the chances of infertility with ABVD were low, so I decided to start treatment as soon as I could.

It took me a little while to understand that I had to put my trust in my healthcare team. Here were a group of people I didn't know but who were making such important decisions about me. They took the time to explain the treatment I would be having and the possible side effects. I asked lots of questions, particularly about relapse, which really worried me, but they explained that there were a variety of options available if this happened.

I had the choice of chemotherapy followed by radiotherapy or more cycles of chemotherapy. My consultant felt it was better to go with chemotherapy alone, particularly bearing in mind my age.

I found the chemotherapy really hard both physically and mentally. On the first day I found it traumatic and was very sick. I had the same problem on the second occasion, and the nurse explained that she suspected I had developed anticipatory sickness that was triggered by the smell of the hospital.

I took a different friend or family member with me to each chemotherapy appointment which I found really helped me.

I managed as much as I could and started to recognise the pattern. For the first couple of days after chemotherapy I would feel very weak, tired and groggy. After a couple of days things would start to improve.

I realised I needed to take it one step at a time and found it was more manageable than I anticipated it would be.

I knew I was going to lose my hair but decided not to shave it off and see what happened. It somehow felt more empowering to me. As it turned out my hair fell out slowly, although by the third chemotherapy it was starting to fall out quickly.

***'I am obsessed with my hair, so losing it was difficult, but I decided to wear wigs and use this time as an opportunity to try out lots of colours and styles.'***

I'm naturally a brunette with long hair and had always wanted to go blond but had never taken that step. In fact, I took the opportunity to try out lots of different colours and styles. I actually surprised myself at how adaptable I was about my hair and enjoyed the variety. It was also far less effort than looking after my own hair!

I had an interim PET scan after my third chemotherapy which showed that I was responding to the treatment. On the scan it looked like there was something in my left breast, which was worrying. The doctor looked into this and reassured me that it was a benign lump caused by hormones from chemotherapy.

I had my last chemotherapy on 15 November 2022 and was told I was in complete remission on 21 December 2022. My boss and colleagues have been really supportive and adaptable and I started back at school after the Christmas break. It was quite soon to return to teaching but it felt right for me.

Going forward, I want to take my health and fitness more seriously and build up my strength and get back to being with my friends. At first, I felt guilty about going out with friends and when I did I felt uncomfortable and overwhelmed. I was worried about my immune system being low and catching something. I also felt more comfortable sticking with a routine. But I realise that staying in made me feel worse and was stopping me from feeling normal again.

Social media really helped me, particularly people who share their stories on Instagram, TikTok and on sites like Lymphoma Action. I wanted to share my story, but I wasn't sure how much I should tell people or how much I should keep it to myself. I felt better being open and avoided awkward conversations with people who I didn't know very well.



Looking back I have found it mentally and emotionally really hard. I started to develop health anxiety and every little thing makes me worry. I suppose I became a bit obsessed with my body about what was right and what was wrong.

Macmillan offered counselling sessions and my GP referred me for 'Change therapy'. It has been described to me as post-traumatic stress disorder (PTSD) as a result of the speed and trauma of the cancer diagnosis. The therapy is definitely helping; I recognise that it helps to reach out and talk about things that are worrying you.



I am very close to my family and friends and like me, the diagnosis was a total shock. They were incredibly supportive but found it really hard to see me going through the diagnosis and then the treatment.

I am very proud of how adaptable I have been and now realise that most of us don't realise how strong we are until we are faced with going through something like cancer. I've still got a lot of 'coming to terms' with this to do but feel far more appreciative of life, far more content and have much more of a zest for life than before this experience.

And I live life by a new motto 'Health is wealth'.

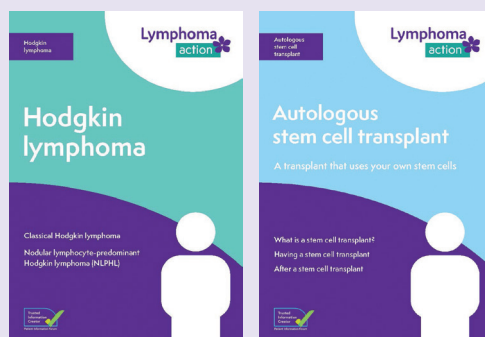
## Updated books now available

We work with professionals in the field to ensure our information is accurate, evidence based and reflects current practice. Our Reader Panel, a group of lay reviewers, also provides insight into whether our information answers all the questions people may have in a clear way. Our medical information is revised every three years, or sooner if there are any changes in treatment. We use diagrams and images, as well as quotes from people affected by lymphoma, to bring the topics to life. We are proud to have the PIF TICK – the UK's only quality mark for health and care information.

### We have recently revised two books.

*Hodgkin lymphoma* covers classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL). It explains these types of lymphoma in detail, including symptoms, diagnosis, tests, treatment and what to expect after treatment.

*Autologous stem cell transplant* is about transplants that use your own stem cells. It explains what a stem cell transplant is and what to expect if you, or someone you know, are having one to treat lymphoma.



You can order Lymphoma Action books free online at [lymphoma-action.org.uk/Shop](https://lymphoma-action.org.uk/Shop) or download them from our website at [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books)

# Patient survey on lymphoma and CLL

Lymphoma Action is a member of the Lymphoma Coalition and together we undertook a UK wide survey, the results of which have been published. The Patient Survey is produced every 2 years and aims to understand patient experience of lymphomas. The 2022 survey also included new questions on the impact of COVID-19 on treatment and care worldwide. The Lymphoma Coalition and its global members use the results to ensure patient voices are heard, driving policy change and tailoring support.



In the UK, **434 people** responded to the patient survey and **54** to the caregiver survey. Here are some headlines from the results.

## Information, guidance and support

Respondents said that doctors (**82%**), nurses (**61%**) and the internet (**48%**) were their most trusted information sources, with patient organisations very closely 4th (**47%**).

Only **21%** of patients felt very well informed about the processes and stages of their healthcare.



**84%** were very satisfied or satisfied with the quality of the information from patient organisations.

**66%** ranked booklets and other written information as their top method of receiving information.

## Diagnosis



- Just over a quarter of patients (**26%**) experienced their symptoms for more than six months before seeking medical care.
- Three out of five patients were seen by three or more healthcare professionals for their symptoms before receiving their initial diagnosis and **14%** were seen by five or more.
- There has been a decrease in the percentage of people told their subtype upon diagnosis of lymphoma. This has fallen every 2 years, and is at its lowest at **62%** in 2022.
- **50%** felt their diagnostic tests and results were explained and the information was understood.



## Treatment

- **56%** said there were no barriers to them getting treatment vs **83%** in 2020. This highlights the impact of the pandemic.
- There has been an increase in the effects of treatment on people's daily lives. **62%** said their side effects negatively impact every day activities vs **56%** in 2020. Again, this may be as a result of the pandemic and many patients having to shield.

### Key reported side effects from treatment:

<b>80%</b> Fatigue	<b>53%</b> Changes in sleep patterns	<b>43%</b> Changes in taste and smell
<b>60%</b> Hair loss	<b>44%</b> Numbness or tingling of body parts	<b>43%</b> Concentration
<b>56%</b> Constipation		

## Impact and experiences of COVID-19

This year the survey included a specific section on the impact and experiences of COVID-19 for those with lymphoma.

- **12%** of patients avoided or delayed seeking medical attention due to the pandemic
- **55%** said their anxiety was worsened during the pandemic and **38%** said their depression was much worse
- Individuals experienced some changes to their care due to COVID-19. These included:
  - caregivers not being allowed with them (**40%**)
  - switching to telemedicine (**27%**)
  - outpatient treatment delayed, rescheduled or cancelled (**26%**)
  - diagnosis delays (**10%**)
  - changes to treatment plans (**9%**).

## Experiences of caregivers

The caregivers' survey highlighted the extensive range of support caregivers provided, and the importance of involving them in decision making too.

**54%** of carers reported being well informed, or very well informed about the processes and stages of the patient's healthcare.



You can read the full report at [tinyurl.com/3uwt29bj](https://tinyurl.com/3uwt29bj)



## Shaken up

**Geoff talks about his lymphoma diagnosis and the challenges of treatment, which included both an autologous and an allogeneic stem cell transplant.**

Back in 2012 I was finishing my three-year training to be a Special Constable in the police force. I was 42 and really looking forward to putting the training into practice. The three years had involved a lot of exercise, so my fitness was better than it had ever been; I had run the London Marathon and ran about six miles daily.

Our warrant cards were presented at a ceremony, and I look back at photos of that day with very mixed emotions. It was a very proud day for me, but I had been struggling with back pain and had lost a massive amount of weight. My uniform was literally hanging off me and I looked really sick.

I thought the pain in my back was as a result of a pulled muscle during training. But it got progressively worse. I saw an osteopath and a chiropractor, which I hoped would sort the problem out, but the pain didn't improve; in fact it was getting much worse.

As a result of the pain, I was struggling to eat and lost 15kg in a short space of time. Looking back, I was also having night sweats but was so worried about the pain, I didn't take much notice of them.

I went to see my GP, and this was followed by an appointment to have an MRI scan. The MRI scan showed that there was something in my lungs, bowel, bones and pelvis. At the time the consultant said it could be lymphoma, but that I would need further tests and a biopsy. Unfortunately it was very difficult to get to the site of the suspected lymphoma and several attempts over the next two weeks were needed to get the tissue. They finally managed to take a sample through my pelvis, however in doing so damaged my sciatic nerve that has left me with loss of feeling and movement in my left leg.

I was diagnosed with stage 4 T-cell non-Hodgkin lymphoma.

***'My first reaction was one of fear and I felt really emotional. Cancer is a frightening word, but I took a lot of comfort from reading about advances in medicine and learning more about lymphoma.'***

There was also an element of relief to finally get a diagnosis as the back pain I had been experiencing had been so debilitating. I started R-CHOP chemotherapy as soon as the diagnosis was made, which I managed well. Whilst having my chemotherapy, the overriding problem I was experiencing was now the hideous neuropathic pain from my left leg damage. This in turn became a major distraction to my cancer. After further consultations and neurologists, the decision was made to install a spinal cord stimulator in my spine to block the erroneous pain messages. Of course, to have further invasive operations whilst undergoing chemotherapy added complications, but the pain I was experiencing was so great, the operations were necessary.

My consultant explained that because of the type of lymphoma I had and how widespread it was, I had a high risk of relapse. Because of this, he thought that following the chemotherapy I should have an autologous stem cell transplant (transplant using my own cells).

The transplant was really tough, but I understood the rationale for it. However, within three months I relapsed in my mesenteric area (a fold of membrane that attaches the intestine to the abdominal wall and holds it in place): somewhere it had not been before. This was a huge blow, and I was starting to feel like I was running out of options.

We talked about having an allogeneic stem cell transplant (transplant using donor cells).

I started another chemotherapy regime to reduce the tumour, but I needed to have an emergency operation on my bowel due to the tumour shrinking, causing four quadrant peritonitis, which landed me in intensive care for two weeks. In this time I suffered an intensive care psychosis, the scariest time of my life. This was to leave me with PTSD (post-traumatic stress disorder) in later life. I was getting worse all the time and they had to stop the chemotherapy until my wounds had healed.

Eventually a donor was found for me, and a year to the day from the date of my autologous stem cell transplant, I started my allogeneic stem cell transplant (using donor cells). The transplant was tough, and in many ways I believe it was even tougher because I had a weakened body. My energy levels were non-existent and I got infections left, right and centre. I remember getting up and going to the toilet and my blood pressure fell so low that I just dropped to the floor. I can still recall the sound of me dropping to the floor and cracking my head on the toilet; I also vaguely recall someone picking me up.

My partner Paula, who is now my wife, was fantastic throughout everything I was going through. Having that support was so valuable during such a challenging time.

I remember the seven weeks of hospital food and just being in the same room, although I was fortunate that it was very comfortable. My wife has told me how she would come in to see me, but for 3 or 4 days I didn't even acknowledge she was there. I also remember the side effects of being on steroids and having no hair or eyebrows. When I looked in the mirror I simply didn't recognise myself.

I had terrible mouth ulcers and struggled to manage my personal hygiene. I felt embarrassed, but realised I had to let that go and quickly appreciated that there was nothing unusual about me compared with others.

***'Coming home from hospital was quite bewildering. I felt like I was being cut loose and that feeling made me nervous.'***

Paula felt even more nervous than I did. As I gradually connected with people again, I realised that life had gone on without me. People had changed jobs, moved house, and I'm not sure I felt like the same person I did before. Everything had changed so much.

I had so many mixed emotions; I was happy to be home but had bouts of anger because I felt this had all been unfair. I then started to resent my home and began to feel a bit like a prisoner there.

My old job had gone after 23 years and it was agreed that I should take on a less demanding role. This was quite a blow. In addition, having just been awarded my warrant card, I was forced to retire on health grounds. I felt I had nothing left, although looking back now the training was so rewarding that I wouldn't have missed it.

I needed to have support with how I was feeling. I was diagnosed with post traumatic stress disorder (PTSD) and Eye Movement Desensitization and Reprocessing (EDMR) therapy was arranged for me. EDMR treats emotional symptoms that follow traumas, such as PTSD, depression, anxiety and panic attacks. It has really worked for me and I am enormously grateful for the way it has helped me cope with my feelings.

I often thought about the person who donated their stem cells for me. After two years you can ask to be put in contact with your donor and I was very keen to meet mine. He was half my age, and at University when he was recruited on the donor register by Anthony Nolan. What surprised me was that he had kept asking his friends and family if he had been good enough. He had no idea of the enormity of the journey I had been on before the allogeneic stem cell transplant, or the gift he had given me.



I think of this experience as having been like being placed in a snow globe. I have been shaken up and the pieces have gone all over the place, but mostly the pieces have settled back to a new normal. It's now over ten years since my allogeneic stem cell transplant and I feel like I am a different person. I can honestly say I have a lovely life now.

Sadly my mother died recently and she wanted donations in her memory to go to Lymphoma Action in recognition of the tremendous support they have given all my family over the last ten years. This was a great gift from her, a legacy if you like.

# A focus on current clinical trials in diffuse large B-cell lymphoma



**Professor Andy Davies, Professor of Haematological Oncology and Joshua Caddy, Senior Trial Manager – Portfolio Lead for Lymphoma, both at the Southampton Clinical Trials Unit at the University of Southampton, provide an update.**

Diffuse large B-cell lymphoma (DLBCL) is the most common of the B-cell lymphomas. It is typically a fast-growing non-Hodgkin lymphoma with an average age of presentation of 70 years but may be seen across all age groups. Clinical trials are ongoing to explore the best treatment combinations, both for first-line treatment and for those whose initial treatment response has not been sufficient/sustained.

## First-line treatment

For many years the standard of care has been chemotherapy with the intravenous drugs cyclophosphamide, vincristine and doxorubicin, and prednisolone steroid tablets. This is combined with a targeted antibody therapy called rituximab, which enhances the activity of the chemotherapy, in a combination treatment called R-CHOP. Patients will generally be given six rounds of R-CHOP administered every 3 weeks. For very many people, this is a highly successful treatment and may be curative.

Unfortunately, however, some patients may not see any benefit from the treatment or will have an initial response but then the disease returns. Over recent decades, researchers have tried to improve upon the

effectiveness of R-CHOP by adding chemotherapy drugs, making the treatment more intensive, using different antibodies or adding new drugs to R-CHOP, but all without significant progress.

## REMoDL-A: a study looking at adding acalabrutinib to R-CHOP

The UK National Cancer Research Institute (NCRI) Lymphoma Group is currently conducting a clinical trial looking to see if a drug called acalabrutinib can improve the effectiveness of R-CHOP chemotherapy. Acalabrutinib is a tablet medicine that has been used successfully to treat other lymphomas, including mantle cell lymphoma and chronic lymphocytic leukaemia. It switches off pathways in the B-cells that are overactive in lymphoma, inducing death of the cells.

A pilot study called ACCEPT looked at the safety of adding acalabrutinib to R-CHOP. It was shown to be safe, did not add to the side effects of R-CHOP and was very effective. Now, acalabrutinib with R-CHOP is being tested against standard R-CHOP in a randomised and unbiased way and in a much larger number of patients to see if it is better than the standard R-CHOP.

This study, run by the Southampton Clinical Trials Unit at the University of Southampton, is called REMoDL-A (Randomised Evaluation of Molecular guided therapy in Diffuse Large B-cell lymphoma with Acalabrutinib). It is being conducted at 50 hospitals across the UK. The study will also try to see if there are patients with particular genetic markers, that we call molecular sub-groups of DLBCL, that may particularly benefit from the addition of acalabrutinib to R-CHOP.

### Refractory and relapsed DLBCL

Unfortunately, some patients may not benefit from R-CHOP chemotherapy and may need an alternative choice of treatment. If there is no reduction in the lymphoma with chemotherapy or the response is very short-lived, the DLBCL is said to be refractory. If the lymphoma has been successfully treated initially but then returns, this is called relapse. Currently, patients with relapsed and refractory DLBCL and who are fit are treated with chemotherapy drugs that work in a different way to those in R-CHOP. If there is a response this is followed-up with high-dose chemotherapy consolidation. Recovery from the side effects of this high-dose chemotherapy is made feasible by collecting stem cells prior to the chemotherapy and then giving them back once the high-dose chemotherapy is out of the system.

R-ICE is a combination of the drugs rituximab, ifosfamide, carboplatin and etoposide and is frequently used in this situation to achieve a response before high-dose chemotherapy. Less intensive chemotherapies are given to those patients who are older or have other medical conditions. The NCRI is currently running two studies adding new drugs to R-ICE in the hope of improving its effectiveness.

These trials are running at different hospitals across the UK to ensure there is good geographical coverage.

### Pola-R-ICE: a study looking at adding polatuzumab to R-ICE

Polatuzumab is an antibody that has a chemotherapy molecule attached to it. It seeks out the lymphomatous B-cells and only when the antibody is engulfed by the lymphoma cell is the chemotherapy activated. This is a targeted way of delivering chemotherapy. It's been used in combination with less intensive chemotherapies up until now and has recently been given NICE approval to be used with R-CHP chemotherapy (no vincristine as the chemotherapy payload is from the same drug family) in patients who have not been previously treated. The Pola-R-ICE in collaboration with the lymphoma study groups from Germany, Spain and Austria is looking at whether adding polatuzumab to R-ICE chemotherapy results in a better response to therapy and a higher chance of going on to a stem cell transplant. This is a randomised study where half the patients will receive polatuzumab with R-ICE and the other half the standard R-ICE. This is a large study of over 300 patients.

### P+R-ICE: a study looking at adding pembrolizumab to R-ICE

Pembrolizumab is an immunotherapy drug that upregulates the immune system to fight against a cancer. It is effective and has become standard of care for many types of cancer, including relapsed and refractory Hodgkin lymphoma. In the P+R-ICE study, the NCRI is looking to see if stimulating the immune system with pembrolizumab when having R-ICE chemotherapy is beneficial in relapsed and refractory DLBCL.

In addition, the trial asks if it helps in the immune recovery phase after a stem cell transplant. The assessment of pembrolizumab in DLBCL is in an earlier part of the clinical trial developmental journey. The P+R-ICE study is looking for preliminary evidence of effectiveness in DLBCL along with safety data. Patients in this study will either receive pembrolizumab with R-ICE or standard R-ICE but there is a weighting towards the combination with pembrolizumab, for every four patients joining the study, three will receive pembrolizumab with R-ICE.

## Considering participating in a clinical trial for DLBCL

It is hoped that this focus on new therapies in DLBCL will improve patient benefit.

The decision to participate in a clinical trial is influenced by many factors including the potential of the treatment to result in a better outcome, possible risks and sometimes the need to have additional hospital visits.

- All studies have been reviewed and assessed by a Research Ethics Committee.
- If you would like to consider participating in a trial, discuss this with your doctor.
- If there is not currently a study operating at your hospital, they will be able to refer you to a centre nearby.
- You will be provided with a very detailed information sheet that will explain thoroughly what it means to be taking part and you will be supported by your local research team.

## Could you provide a patient perspective?

The teams running these clinical trials are looking for people with experience of DLBCL, or another lymphoma, to become public contributors on the trial management teams.

These contributors help to give a patient's perspective to the way trials are run and help review patient-facing documents. If you are interested in getting involved, please visit the Patient and Public Involvement pages of the Southampton Clinical Trials Unit website: [www.southampton.ac.uk/ctu](https://www.southampton.ac.uk/ctu)

If you are interested in a role in the PRICE trial or have any other questions, please email Amber Cole, Trial Manager – [PRICETrial@soton.ac.uk](mailto:PRICETrial@soton.ac.uk)

If you are interested in a role in the REMoDL-A trial or have any other questions, please email Nicole Keyworth, Senior Trial Manager – [remodla@soton.ac.uk](mailto:remodla@soton.ac.uk)



Find out more about clinical trials at [lymphoma-action.org.uk/TrialsLink](https://lymphoma-action.org.uk/TrialsLink)

Lymphoma Action's Lymphoma TrialsLink will explain more about clinical trials, explain how drugs are developed and approved and has a list of questions you might like to ask about clinical trials. Our 'Find a trial' contains a list of lymphoma-specific trials.



# Top Tips: travel

If you are planning to travel or go on holiday, and are affected by lymphoma, there may be some additional things to consider.

We asked our closed Facebook Support Group for their 'top tips' and suggestions for planning a trip away. *Thanks to everyone for their ideas.*

## Planning your trip

- Talk to your specialist or CNS if you are unsure whether it is safe for you to travel (this could be around planned treatment or considering if your immune system is lowered). Your travel insurance company may need a letter from your healthcare professional to confirm this.
- It is a good idea to research your destination. Are there medical facilities or a hospital nearby if you need them? How will you be travelling - is there public transport? What is the terrain like - is the area hilly or flat (as this might be important if you get fatigued)?
- You might like to write a check list of all the things really necessary for your trip (such as your passport, travel tickets, travel insurance information, parking instructions) in advance. Then you can check them off on the day you travel just before you go.

## Medication and medical information

- It can be helpful to take a copy of your hospital letter with your diagnosis, and your most recent follow-up letter. It can also be useful to have a list of any treatment you have had and medications you are on. You may need to provide this to explain your condition.
- If you are prone to infections, consider talking to your medical team about supplies of antibiotics or any other medication that you may need while you are away.
- Some countries may require you to take medication in its original packaging (rather than just strips of pills or a pill or dosette box). It is often worth checking the situation in your destination country well before you travel.
- Check what travel vaccinations you need for the country you are going to. Some vaccinations need to be given well before travel, so seek advice at least 8 weeks before your trip. It is also a good idea to talk to your medical team about your childhood inoculations (as some treatment may mean that they are no longer effective).



## Insurance and GHICs

- It is important to have the right travel insurance for your trip; it may be worth speaking to a number of companies to ensure you get the right cover for you and your situation. You can call our helpline to talk about travel insurance companies.
- Apply for a GHIC (Global Health Insurance Card - which replaces the EHIC). This is not a replacement for travel insurance, but allows you to access 'medically necessary state-provided healthcare' if you are visiting an EU country or Switzerland. (Visit [www.nhs.uk](https://www.nhs.uk)).

## Travelling and packing

- Take paper photocopies of key documents (your passport, driving licence, GHIC card) just in case you lose your originals, and keep these copies separate from the originals!
- Keep a record of key information (the serial numbers for your mobile, camera etc) just in case you lose any items and need to make an insurance claim.
- Consider keeping some cash or a credit card separate from your other money - just in case!
- If you are taking medication, pack some extra. You could split it between your flight and hand luggage, in case any luggage is lost. You might need a medical letter explaining why you have this medication, particularly if you have any of it by injection.
- When travelling with others, consider splitting your clothes between different suitcases: this is helpful if one goes astray (and taking a photo helps with claiming lost luggage).
- Consider packing enough clothes for a day or two, and anything that you can't manage without, in your cabin luggage (in case your suitcase goes astray). Check the rules about luggage weights, and security checks with your particular travel/airline company.
- You may want to take face coverings, antiseptic wipes and hand sanitiser with you, including in your hand luggage (so you can wipe armrests or tray tables).
- Remember to keep hydrated while you are travelling and during your trip. Check whether to use bottled (not tap water) in the country you are travelling to (if in doubt use bottled).
- If you are ordering drinks, you could consider asking the cafe or restaurant to steam your glass or cup first (flushing the glass or cup with steam or hot water to clean it).

## Once you get to your destination

- Some chemotherapy and radiotherapy can leave your skin more sensitive to sunlight. It can be helpful to avoid being in the sun, or wear sunscreen with an SPF of 30 or higher with both UVB and UVA protection. Wear sunglasses with a UV filter, and consider wearing a wide-brimmed hat (to cover your scalp, neck and ears) and cover your skin with clothes such as long-sleeved shirts and trousers.
- Don't underestimate how tired you are likely to feel after your journey. Allow plenty of time to recover when you get there.
- Remember, although you may need plenty of rest and relaxation, you are on holiday – enjoy yourself!

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](mailto:publications@lymphoma-action.org.uk) or join our Closed Facebook Support Group at [facebook.com/groups/LymphomaActionSupportUK](https://facebook.com/groups/LymphomaActionSupportUK)

# New range of Online Support Meetings (OSMs) launched

**We understand the importance of people being able to connect with others affected by lymphoma. Our Lymphoma Action Online Support Meetings (OSMs) provide people affected by lymphoma a place to feel safe to express their thoughts and feelings, gain insight from connecting with peers and access information and support.**

Our OSMs are one of a number of peer support services offered by the charity and are facilitated by a mix of trained volunteers and members of Lymphoma Action staff. In January we were excited to launch our new range of OSMs.

Building on what we learned over the past two years, and responding to feedback we have received, we are delighted to be able to offer access to this vital support across the whole of the UK. Our OSMs are available to people diagnosed with lymphoma and their family, friends, and carers.

The new range of OSMs continues to provide general online support meetings for all, across England, Scotland, Wales, and Northern Ireland. Our Young Adults, and Family, Friends and Carers meetings continue, and the popular Special Focus Support Meetings have become monthly, giving those affected by particular topics, such as fatigue, stem cell transplants and sleep disturbance, an opportunity to benefit from peer support by others similarly affected.



We also have four new specific group meetings:

- active monitoring
- advanced and refractory lymphoma
- rare lymphomas
- cutaneous (skin) lymphoma.

We will also offer introductory sessions roughly every six weeks, to provide a 'tour' of these and other Lymphoma Action support services and information.

The OSMs are open to anyone over 18 years of age and resident in the UK who is affected by lymphoma. 'Being affected' means having a diagnosis of lymphoma or being close to someone who has, such as a partner, friend, or family member.

***'I would just like to say thank you. We have just finished today's online support meeting and I, once again, found it so very helpful to talk and listen to others with similar experiences. It's supportive, refreshing, reassuring and informative every time. I am always glad I attended, (or sad if I missed one) and would recommend them to anyone touched by lymphoma- however near or far from diagnosis and treatment. Thanks.'***

OSMs are delivered using our authorised Zoom accounts and are an hour in length. They are designed to maximise the time for participant sharing and mutual support.

These meetings are not designed for those who are seeking counselling, therapy, or bereavement support. If you are looking for this sort of support, you may like to contact our Helpline Services for details of other organisations that may be able to help.

We continue to offer telephone, Live Chat, and email support via our Helpline and Buddy services, and our Live your Life self-management support will offer both online and regional face-to-face workshops.



We are excited to have launched this new range of OSMs and hope our lymphoma community will welcome this change. Several of the new meetings are already attracting high numbers of registrations, so we will review the frequency and timings of these to ensure we provide a meaningful and supportive experience for everyone. We appreciate the patience and support of the community if we need to make changes as the year ahead unfolds!

***'I hugely appreciate all the help you are giving me. To say 'thank you' just doesn't cover the extent of your help!'***

We recognise that not everyone wants or is able to access support online, and we will continue to closely monitor and evaluate all of our services to ensure we offer something for everyone.

***Dallas Pounds, Director of Services***

## Lymphoma Action services – here for you

**Helpline Services** – for information and emotional support, call freephone **0808 808 5555**, or use Live Chat on the website, 10am to 3pm, Monday to Friday. Or email [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)

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

**Closed Facebook Support Group** – join this popular group at [facebook.com/groups/LymphomaActionSupportUK](https://facebook.com/groups/LymphomaActionSupportUK)

**Webinars** – we host webinars on a range of topics. Find out what is coming up at [lymphoma-action.org.uk/events](https://lymphoma-action.org.uk/events)

**Videos** – we have videos on various topics around lymphoma. Find out more at [lymphoma-action.org.uk](https://lymphoma-action.org.uk)

**Lymphoma Voices** – our podcast series includes personal experiences and medical opinion. Find out more at [lymphoma-action.org.uk/LymphomaVoices](https://lymphoma-action.org.uk/LymphomaVoices)

**Live your Life** – virtual self-management workshops to help you improve your wellbeing after treatment or if you are on active monitoring. Find out more at [lymphoma-action.org.uk/LYL](https://lymphoma-action.org.uk/LYL)

**Online Support Meetings** – we have regular meetings throughout the UK, including for family, friends and carers and for young people (18 to 35). Find out more: [lymphoma-action.org.uk/OSM](https://lymphoma-action.org.uk/OSM)

# One weekend, two fantastic events!

## Lymphoma Action National Conference

Reconnecting the lymphoma community

Saturday 13 May 2023, etc.venues County Hall, London

We are delighted to welcome you back to our biggest event of the year! Join us to meet others affected by lymphoma, lymphoma specialists and the Lymphoma Action team.

Tickets £30. Book online: [lymphoma-action.org.uk/NationalConference](https://lymphoma-action.org.uk/NationalConference)

Got a question? Email [conferences@lymphoma-action.org.uk](mailto:conferences@lymphoma-action.org.uk) or call 01296 619412.

## Join #TeamLymphoma on Sunday 14 May for our brilliant Bridges of London Walk

It's a family-friendly, 7 mile walk across 11 of London's most iconic bridges, taking in the sights of our Capital's best landmarks.

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



Find out more or sign up at: [lymphoma-action.org.uk/Bridges23](https://lymphoma-action.org.uk/Bridges23)