

# lymphoma matters

ISSUE 126 | SUMMER 2023



Lymphoma  
action 



# let's talk lymphoma



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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: Christine, who shares her story on page 12.  
Photo: Anthony Wood

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

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Ropinder Gill  
Chief Executive

Find out about the opportunity to join the Buddy Service, just one of our many volunteering roles, on page 35.



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)

## Celebrating achievements and community

Welcome to this summer's edition of Lymphoma Matters.

I write this introduction off the back of a wonderful Volunteer Recognition event, held online to celebrate the amazing contribution of our 250+ volunteers. We were delighted to be joined by Emma Forbes and her sister Sarah Standing to recognise the special contributions and long service of our volunteers. Sarah was diagnosed with lymphoma during COVID. I'd like to take this opportunity to thank each and every volunteer and those who couldn't attend the event yesterday.

We're proud of what you all help us to accomplish – you can find out more about what we achieved in 2022 and our plans for the future by reading our annual report and accounts at [lymphoma-action.org.uk/Accounts](https://lymphoma-action.org.uk/Accounts). The accounts include more detailed information about our finances and how we're governed.

We hope you'll see our values reflected in the way we run and manage Lymphoma Action. This is important because every pound that is given to us, every annual draw ticket sold, every regular gift or legacy given, is given to make a difference and to support others. And this is something we aim to do more of as we develop some new and exciting services in the coming year.

Charities provide some of the most important services for our society and are rightly held to high standards and Lymphoma Action is no different. We pride ourselves on what we do and how we do it and much of this is thanks to our amazing lymphoma community. Thank you for your continued support.

**Ropinder Gill**  
Chief Executive

## Translated animations

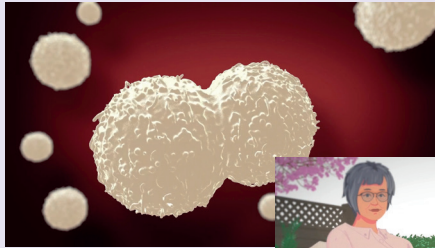
Our two animations, *What is lymphoma?* and *About Lymphoma Action* are proving to be really valuable resources to help people understand their condition and how we may be able to support them. So much so, that we have translated them into three languages: Polski (Polish), ਪੰਜਾਬੀ (Punjabi) and Română (Romanian).

### *What is lymphoma*

Co to jest chłoniak (Polish)

ਲਮਿਫੋਮਾ ਕੀ ਹੈ (Punjabi)

Ce este Limfomul (Romanian)



### *About Lymphoma Action*

Lymphoma Action (Polish)

Lymphoma Action ਬਾਰੇ (Punjabi)

Despre Lymphoma Action (Romanian)



You can find these animations at [lymphoma-action.org.uk/Translations](https://lymphoma-action.org.uk/Translations)

## Revised information now available

### *Introduction to lymphoma*

We've worked with experts to update our *Introduction to lymphoma* book. This book gives an overview of lymphoma including information about what lymphoma is, tests and scans, different types of treatment and living well with and beyond lymphoma. Our book includes quotes from people affected by lymphoma as well as illustrations and diagrams.



### **Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)**

Our webpage on CLL and SLL has just been revised. It explains about CLL and SLL in detail and includes an explanatory video. The information also includes quotations and links to others who have lived experience of treatment for these low-grade non-Hodgkin lymphomas.

You can download *Introduction to lymphoma* at [lymphoma-action.org.uk/Information](https://lymphoma-action.org.uk/Information) or order a copy free of charge through our shop: [lymphoma-action.org.uk/Shop](https://lymphoma-action.org.uk/Shop)

## Latest guidance from NICE

At Lymphoma Action we are proud to ensure the patient voice is heard by contributing to Health Technology Assessments for lymphoma treatments. We continue to advocate for better treatment options to improve outcomes for people affected by all forms of lymphoma.

Over the past month, the National Institute for Health and Care Excellence (NICE) has published new guidance for lymphoma treatments. We are pleased to see two new treatments recommended.

- NICE has recommended **ibrutinib plus venetoclax** as an option for adults with untreated chronic lymphocytic leukaemia (CLL). Both venetoclax and ibrutinib are targeted cancer drugs. Venetoclax is a BCL-2 blocker which destroys cancer cells by stopping them growing and surviving. Ibrutinib destroys cancer cells by stopping them dividing. They are both currently used as treatment options for CLL but not combined. The combination is therefore a positive addition to CLL treatment.
- **Axicabtagene ciloleucel** is a type of CAR T-cell therapy. This treatment uses your own immune system to try to destroy lymphoma cells. NICE has recommended axicabtagene ciloleucel for use within the Cancer Drugs Fund as an option for the treatment of relapsed or refractory diffuse large B-cell lymphoma when an autologous stem cell transplant is suitable if:
  - the cancer has relapsed within 12 months after first-line chemo-immunotherapy; or
  - it has been refractory to first-line chemotherapy.
- NICE has **not** recommend **mosunetuzumab** for the treatment of relapsed or refractory follicular lymphoma in adults who have had two or more systemic therapies (drugs that work throughout the whole body).
- NICE has also **not** recommended **axicabtagene ciloleucel** for treating relapsed or refractory follicular lymphoma after three or more systemic treatments in adults.

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





## Spotlight on: Chemotherapy



**In March, Lymphoma Action hosted a webinar on chemotherapy, covering what it is, how it works and why it is used.**

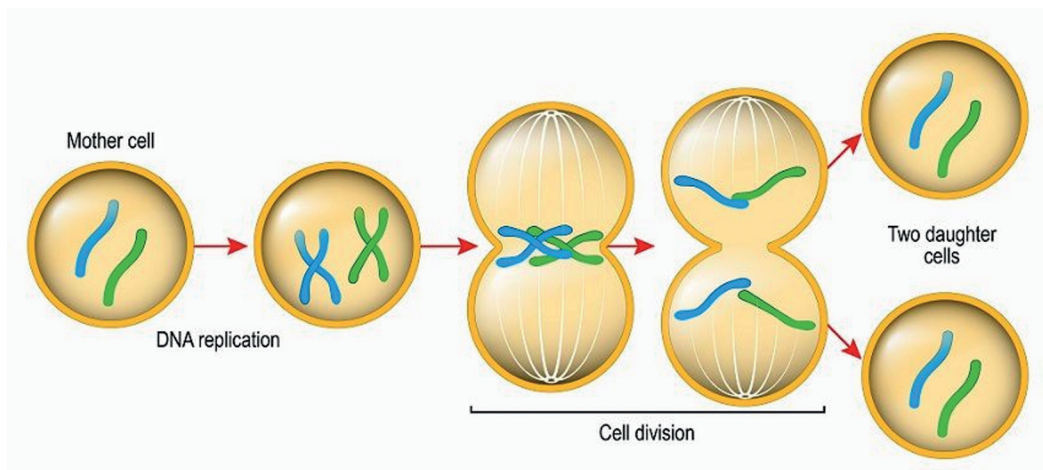
This article covers the key points from the presentation given by Consultant Haematologist Professor Graham Collins. The full webinar, including a presentation by Haematology Nurse Clinician Ruth Jackson, focuses on the more practical aspects of what to expect when having chemotherapy. The webinar can be viewed on our website: [lymphoma-action.org.uk/Chemotherapy](https://lymphoma-action.org.uk/Chemotherapy)

### **What is chemotherapy and how does it work?**

Chemotherapy simply means 'treatment with drugs', however nowadays it is usually used to mean treating *cancer* with drugs.

To work, chemotherapy relies on the fact that cancer cells divide more than regular cells. There are many stages in the process of cell division. Some chemotherapy drugs target cells which are at a specific stage in this process, whereas others target cells at any time during this division.

## Process of cell division



### Why do we use chemotherapy to target cancer cells?

There are two reasons why chemotherapy drugs are used to target cancer cells:

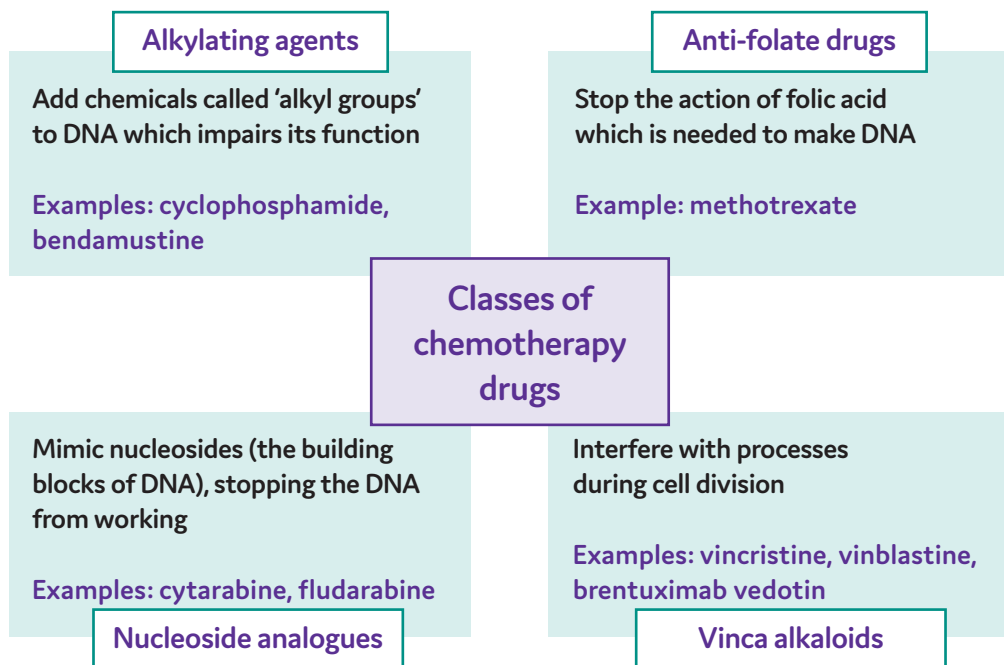
- Cell division in cancer cells is unregulated, dividing much more often than normal cells. This means that drugs which target cells in this process will kill cancer cells preferentially over normal cells.
- Cancer cells are not very good at repairing DNA. Some chemotherapy drugs work by damaging a cell's DNA. Normal cells can recognise and repair this damage under normal circumstances, whereas this damage can kill cancer cells.

Some normal cells in the body are constantly dividing and these can be affected by chemotherapy. This can cause the side effects you often hear associated with chemotherapy:

Dividing cells affected	Potential side effect
Gut lining	Nausea, diarrhoea
Hair follicles	Hair loss
Bone marrow	Increased risk of infection

### What drugs are used for chemotherapy?

There are many different types of chemotherapy. Each drug works in a different way, and everyone's experience with chemotherapy can be very different. Professor Collins outlined four main groups, or classes, of chemotherapy, and there are different drugs within each class.



### Why do we combine different chemotherapy drugs?

Chemotherapy is often given in regimens, which are combinations of drugs.

This approach:

- allows the chemotherapy to target cells at different stages in the process of cell division at the same time
- reduces the chance of resistance developing by using drugs that work in different ways
- balances the toxicity of treatment by using drugs associated with different side effects.

### How much chemotherapy is given and when?

Clinical trials are used to determine the highest dose of chemotherapy which is safe to give, on its own or in combination with other drugs. The specific dose given to an individual will vary depending on multiple factors, such as:

- height and weight, to give the body's surface area
- kidney and liver function, as the chemotherapy is excreted via these organs
- any other drugs they are taking, as they may interact with the chemotherapy
- any other medical issues, as they may make chemotherapy more risky.

For every chemotherapy regimen there is a protocol which clinicians follow that details how to adjust doses to account for these factors.

Chemotherapy is usually given in cycles over a few months:

- It allows the chemotherapy to kill more cancer cells. As chemotherapy only works on dividing cells, some cells will not be killed during a single treatment.
- The rest between treatments allows time for the body to recover from any side effects.



### Why are different regimens used?

There are many different chemotherapy regimens available for lymphoma treatment. The type and stage of lymphoma will determine potential treatments, however deciding the most appropriate option for a specific individual involves asking a series of questions.

- **What is the aim of the chemotherapy?**

A more aggressive approach, including side effects, may be more acceptable if the aim is to achieve a cure.

- **Are there any other medical issues?**

Certain chemotherapy drugs are not suitable in the presence of specific medical conditions.

- **What does the individual want?**

Preferences are important when considering the pros and cons of alternative options.

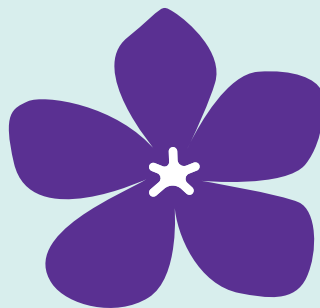
**With thanks to Professor Graham Collins for reviewing this information**

### What's it like to have chemotherapy?

In April, Lymphoma Action held a webinar focussing on the experience of having chemotherapy, talking to people with lived experience of chemotherapy treatment for their lymphoma, and a clinical nurse specialist. Watch the webinar online on our website: [lymphoma-action.org.uk/Chemotherapy](https://lymphoma-action.org.uk/Chemotherapy)

## Did you know?

The periwinkle on our logo has cancer-fighting properties. The periwinkle was not chosen just because it makes an attractive logo. There is far more to this plant than its evergreen foliage and pretty small flower.



The Madagascar Rosy periwinkle or *Catharanthus roseus* has significant medicinal properties that have been used in traditional Chinese medicine for centuries, for many conditions, from diabetes to depression.

In the 1950s, a Canadian research team identified the compounds in the Madagascar periwinkle that have cancer-fighting properties. Since then scientists have been extracting a chemical called vinblastine from its leaves. Vinblastine and vincristine are used in the treatment of Hodgkin lymphoma and childhood leukaemias.

So important is this plant's properties, that plant scientists have been trying to unravel the complex chemistry of the Madagascar periwinkle and its cancer-fighting properties. In 2018, after 15 years of research, a team at the John Innes Centre, together with the Courdavault group based at Tours in France, located the missing genes in the genome of the periwinkle that build the chemical vinblastine.

The periwinkle is a remarkable plant and we are proud to have it as part of the Lymphoma Action logo.

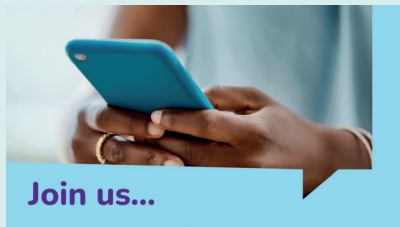


# Let's talk lymphoma!

We are counting down to our biggest month of the year! September is Blood Cancer Awareness Month and we aim to get as many people as possible talking about lymphoma, increasing awareness and raising vital funds along the way.

There are so many ways you can get involved.

- **What is lymphoma?** Help us share symptoms and raise awareness.
- **Join us to do more.** Get involved and become one of our champions (see opposite).
- **Share your story.** Let us know what you can do to make a difference this September, and inspire others to join in too.



It's easy to get involved, either from the comfort of your sofa or out and about taking on a challenge. What will you do this September to make it our biggest ever Blood Cancer Awareness Month? See [lymphoma-action.org.uk/LetsTalk](https://lymphoma-action.org.uk/LetsTalk) to find out more.

## A massive THANK YOU!... #TeamBridges

On Sunday 14 May, 304 people (and many adorable doggies), joined us to walk the Bridges of London... with another 62 of you taking on walks closer to home.

It was our biggest turnout ever and together, (including Gift Aid) you have raised over **£64,000!** That's the most ever raised from our Bridges events by miles and we really cannot thank you enough for helping make sure no one has to face lymphoma alone. Just to give you an idea of the simply extraordinary difference you have made, that's enough for us to send vital information to every single one of the 20,000 people who receive the life changing diagnosis of lymphoma every year.

*We are so grateful, thank you!*



# Let's talk champions!

So far this year £30,000 has been raised by local sports teams, clubs, societies and companies.

Often inspired by a colleague or teammate, these organisations have done truly remarkable things to support us - from head shaves to bake offs, walks to ice hockey games and from those making a single donation to those taking on incredible challenges to honour someone special. We are beyond grateful for their dedication.

Most reading this magazine will have a link to an employer or sports club, a local group or organisation. We are asking you today to introduce them to Lymphoma Action. Could you be our champion and help them find us? We have an expert team of fundraisers waiting to support their efforts.

One link to one employer could create a long-term partnership. They may choose us as their charity of the year and enable us to raise awareness among potentially hundreds of employees and their families. So please, talk to your colleagues and friends about lymphoma, and help us raise awareness and funds.



Contact Amy or Deana today at [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk) or on 01296 619400. Thank you – we simply cannot do this without you.





## The courgette that saved my life

### How a courgette started a chain of events that led Christine to a diagnosis of lymphoma.

It was an ordinary Monday evening just before the COVID-19 lockdown. I was preparing my evening meal which was going to be salmon with rice and a courgette, cooked in the microwave. But as I turned in my galley kitchen to put the courgette in the microwave I fell to the floor and could not get up. Could I slither to the phone? No, I thought, it is best to press my personal alarm to get some help.

Very soon two friends arrived. They insisted on calling the ambulance for professionals to help me up as they were afraid of causing an injury. When the two paramedics arrived after only about twenty minutes, they easily helped me up but wanted to do some tests.

To my surprise they found a heart murmur and decided they should take me to hospital to have it checked.

I had nothing packed for a hospital stay, but my friend Janet managed to get the necessary things together. She was brilliant. Since then I always keep a holdall packed for a hospital stay. Of course, I have not needed it!

There was a long wait in A&E and I was getting very hungry having missed my evening meal at home and arrived too late for one at the hospital! However, a nurse kindly managed to find me a sandwich once I was admitted to a ward.

I was well looked after in the hospital. A physiotherapist visited daily once they found that my injury from the fall had caused a squashed vertebra in the lower back. A heart specialist (cardiologist) visited and prescribed medication for the heart murmur.

One day a haematologist arrived at my bedside closely followed by a group of fresh-faced student doctors. Or at least I presumed they were student doctors as they seemed young. But then at 87, so do most people. He said there were signs of cancer in my blood, but he needed to do more tests to be sure. He said he would probably prescribe chemotherapy. The students took notes. I was amazed. Nobody in my family had experienced cancer, although nobody had lived into their eighties like me.

The back injury gradually healed with the help of the physiotherapist. After my return home my haematologist arranged several appointments for me; at least three scans and several biopsies. Eventually a biopsy on a swollen gland in my neck gave him the information that it was lymphoma.

For me, my cancer caused no pain. A blood test by my GP had come back clear just a few weeks earlier when I had reported the swollen gland.

*I thought 'Oh good, we have a result'. Closely followed by 'Oh, I have cancer'.*

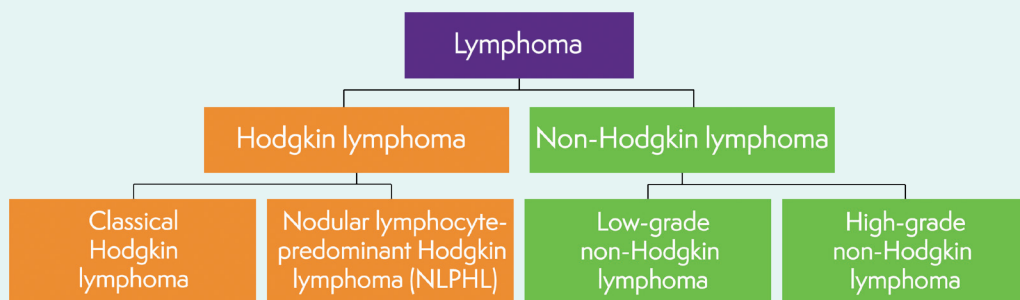
I was diagnosed with stage 3 lymphoma and a course of chemotherapy was arranged which completely destroyed the cancer and did not give me any serious side effects.

I could not have had better treatment anywhere. Of course, I also have my little courgette to thank. Without it causing my fall, it is unlikely I would ever have met my consultant, or certainly not until it was too late.

## Did you know?

**Lymphoma is the 5th most common type of cancer in the UK.**

There are over 60 different types, broadly grouped into Hodgkin lymphomas and non-Hodgkin lymphomas. Non-Hodgkin lymphomas are further grouped depending on whether they are slow-growing (described as 'low-grade' or 'indolent') or fast-growing ('high-grade' or 'aggressive'). Different types of lymphoma behave differently and need different treatment.



Lymphoma, leukaemia and myeloma are all types of blood cancer (also called 'haematological' cancers). Although there are similarities between some types of lymphoma and leukaemia, most types develop differently. They also behave differently and are treated differently.

# Talking about stem cell transplants

We recently recorded a podcast about stem cell transplants where Angie Leather, Lead Nurse for Transplant and Haematology CNS, and John Murray, Nurse Clinician in BMT (bone marrow transplant), both from The Christie Hospital NHS Foundation Trust, talked about stem cell transplants.

There was a lot of discussion on this topic and here are just a few points from that podcast.



## What is the difference between an autologous and an allogeneic stem cell transplant?

An autologous transplant uses cells from the patient themselves and an allogeneic transplant uses cells directly from a donor.

## Why might I be considered for a stem cell transplant (SCT)?

It depends on how well you responded to treatment. Someone with Hodgkin lymphoma, for example, may never need a transplant; their initial treatments may do very well, and they may go into remission and remain in remission.

An autologous or allogeneic SCT may be required if lymphoma has come back (relapsed) and isn't helped by standard chemotherapy alone or is very likely to come back. Your medical team need to be able to consolidate it with a bigger dose of

chemotherapy. So much so that it would destroy the bone marrow that you've got. We then help remedy this through a stem cell transplant.

## What type of transplant is appropriate for me?

Autologous SCT is gold standard treatment for lymphoma. However there are some circumstances where lymphoma is difficult and treatment might not be working as well as hoped. In these cases, an allogeneic SCT might be considered more beneficial.

The chemotherapy doses vary between an autologous and allogeneic SCT and the possibility of things going wrong are higher with an allogeneic SCT. This is because of the risk of side effects such as graft-versus-host disease (GvHD). However, having an allogeneic SCT might give a greater chance of achieving a long term remission, or never needing treatment again.

It's important to consider the benefits versus the risks of having a SCT, which can be a difficult decision. You need to have all the information before deciding on the best option, which is why you are likely to have several discussions with your treating team. We really encourage you to ask all the questions you need.

## Where are donors found for an allogeneic SCT?

The transplant team will assess whether you are eligible for an allogeneic stem cell transplant, considering several things including cardiac function and other factors. If you are suitable, samples will be taken to look at your genetic makeup, or DNA.

The first place to look for donors is with siblings. If you have a brother or sister, they will be approached and asked questions to assess whether they are suitable. If they are, then a blood sample will be taken to do tissue typing to see if they are a match. There is about a one in four chance of a sibling being a match.

If they're not a suitable match, there are other avenues to explore such as the Anthony Nolan register.

### The Anthony Nolan register has about 36 million donors worldwide.

Transplant teams are also able to look for donors in Europe and across the world. Transplants can be from adult donors, umbilical cords or, more recently, haplo-identical (often called haplo), or half-match donors are considered. This is usually your parents or your child, but it is more difficult to undertake this type of transplant.

## What is the process for a SCT?

For an **autologous SCT**, you'd usually be referred to a transplant centre to talk through the process with the clinicians. If it is felt that a SCT is the right way to go, you would then have a medical assessment to make sure you are fit for the treatment.

The stem cells then need to be taken from you. This is called 'stem cell collection' (or mobilisation). Stem cells are made in the bone marrow and to be able to collect them from you, the team boost the cells and move them into the bloodstream using a drug called G-CSF (granulocyte-colony stimulating factor).

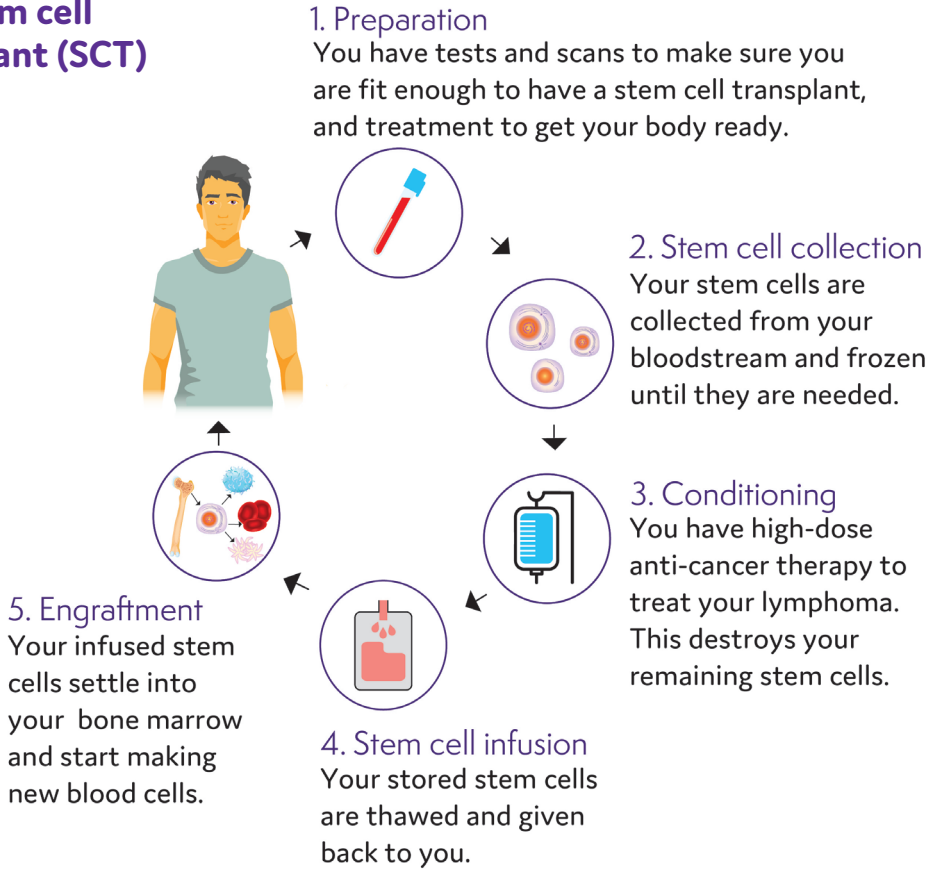
You are given chemotherapy followed by injections of G-CSF to produce enough stem cells. The stem cells are removed using a machine (this process is called apheresis) and the process takes about 4 to 6 hours, after which you can usually go home. The cells are then taken to a lab and frozen for storage ready to transplant.

For an **allogeneic SCT** it is the donor who will go through the process explained above, but without the chemotherapy; they'll just have the injections for a few days beforehand to mobilise the stem cells. Umbilical cords are stored frozen at birth and are transported to the recipient centre for infusion when required.

## How do I receive my own or donor blood cells?

Once admitted into the hospital, you're usually given about 5 to 6 days of chemotherapy, depending on the chemotherapy regime. Then, about 24 to 48 hours later, you'll get the stem cells back through a drip in your arm or into your central line. Some people feel it is a bit of an anti-climax.

## The stem cell transplant (SCT) process



### How long is recovery?

It varies a lot, particularly if you've had an allogeneic transplant. John explains that he often says to people, 'give yourself a year from the day you received your cells' as a good indication.

Once you have been discharged, it's your full-time job to get better. To do that it's important you eat and drink the right things, take any medication, do physical activity and mentally stimulate yourself. It might feel boring, and you might not feel like doing it every single day, but you should consider it as a continuation of your treatment, and the effort will pay off.

### What about side effects?

There can be a lot of side effects, which will be discussed with you at the pre-transplant appointment. The side effects from an autologous SCT tend to be less severe and tend to wear off more quickly compared with an allogeneic SCT.

### Find out more

Lymphoma Action has revised their book *Autologous stem cell transplants*. Download a copy from [lymphoma-action.org.uk/Books](https://lymphoma-action.org.uk/Books) or order a free copy at [lymphoma-action.org.uk/Shop](https://lymphoma-action.org.uk/Shop). Find out more about both autologous and allogeneic SCT at [lymphoma-action.org.uk/SCT](https://lymphoma-action.org.uk/SCT).



## Beating the odds is not without its challenges



Our Information and Support Officer Neil reviewed John's book *Me and My Shadow*:

Having been diagnosed with lymphoma at the age of 18, this is a frank, honest and courageous account of what the author describes as 'a unique and unparalleled journey', which made him the person he is today. It is a book well worth reading and I enjoyed sharing the emotional ups and downs of this journey with him. He describes the kaleidoscope of emotions where in his own words he 'found the strength to overcome adversity and look forward to tomorrow'. He balances the joys of parenthood with the devastation of hearing that his beloved daughter Donna had also been diagnosed with lymphoma at a very young age.

Listen to John's incredible story at [lymphoma-action.org.uk/Podcast#john](https://lymphoma-action.org.uk/Podcast#john)



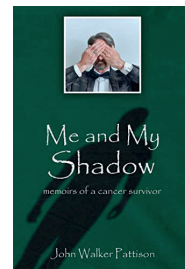
We have recently released a podcast in which John shares his experience of lymphoma. His story begins almost 50 years ago in the shipyards of Newcastle and a diagnosis of Hodgkin lymphoma that was kept from him. In a twist of fate, his daughter also received a blood cancer diagnosis.

In the podcast John talks frankly about his emotional lymphoma experience which led him to a career as a lymphoma clinical nurse specialist and more recently an author (see book review in the next column). He talks about what helped him through some dark times and how he feels about being one of the longest cancer survivors.

Initially it was thought that the lymphoma would end John's life, but that didn't turn out to be the case. He's enjoyed professional success and written children's books. He has been inspired by the rock band Hawkwind and found inspiration from the Lakota Sioux Nation.

John now spends time in his retirement with his wife, grandchildren and great grandchild. It is an inspirational story of a life in the author's words 'lived to the full' and having 'enjoyed each and every day as it happened'.

*Me and My Shadow* by John Walker Pattison is available through booksellers.



# Let's talk community

Whether you're holding a fundraising event, taking on a challenge, raising awareness, bringing together your local community or volunteering your time – we'd love you to get involved.

Support our vital work and talk lymphoma this Blood Cancer Awareness month. Perhaps you could organise a sponsored talk and walk with friends and neighbours? Maybe a chat over coffee and cake is more appealing to you, and you could involve colleagues at work?

Whatever you choose to do, we would love you to talk lymphoma this September, helping us raise awareness and ensure that no one faces lymphoma alone.

To tell us about your fundraising plans visit [lymphoma-action.org.uk/Fundraise](https://lymphoma-action.org.uk/Fundraise) call 01296 619400 or email [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk)

# Let's talk regular giving

A little gift can go a long way, which is why a monthly donation to Lymphoma Action is a simple way to make a really big difference.

Regular gifts give us a stable source of income, helping us plan for the future and reach our aim of ensuring that no one faces lymphoma alone.

Over the course of a year a regular donation of £2 a month could cover the cost of a call to our specialist Helpline, allowing someone to talk about lymphoma and get the information and support they urgently need.

Our knowledgeable and friendly team is available to offer information and provide a listening ear to those affected by lymphoma. Talking things through, confidentially, with someone who really understands makes the world of difference. How many calls could you support with your chosen monthly gift?

To set up a regular gift visit [lymphoma-action.org.uk/Donate](https://lymphoma-action.org.uk/Donate) call 01296 619400 or email [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk)

# Be inspired

At time of writing, our 2023 London Marathon Team of 74 people has raised more than £166,000 for Lymphoma Action with money still coming in. After many hundreds of training miles between them, they faced one magic race day with courage, humour, pride and determination.



*'There really is no feeling like it, the sheer joy at crossing the finish line while total strangers cheer you through is indescribable. The fact that as a team we have raised such a huge amount for this charity is incredible.'*

2023 London Marathon runner



Feeling inspired? Apply for a place on our 2024 team today at [lymphoma-action.org.uk/LondonMarathon24](https://lymphoma-action.org.uk/LondonMarathon24) and make next year amazing!

Check out other running events with available places at [lymphoma-action.org.uk/Run](https://lymphoma-action.org.uk/Run)



**Be persistent if you think something is wrong!**

## Neil talks about his diagnosis of Hodgkin lymphoma.

In 2021, I was 36, married with two girls and leading a busy life. I was fit and healthy, having completed the London Marathon in October 2021. I had no family history of health issues, with the only minor thing being asthma caused by hay fever, which was very mild.

In January 2022, I developed a bad cough which I suspected was COVID, although the tests all came back negative. As it didn't improve, I went to see my GP who, over a number of appointments, tried all the usual things like inhalers, antibiotics and steroids. I had to keep chasing my doctor for appointments and tests because I knew things weren't right and wasn't prepared to let it go. It's one of the messages I really want to give in my story because for me it was so important to be persistent.

By May 2022, the cough was keeping me up at night and I was starting to bring up a lot of stuff. The GP had done everything at a local level, so referred me to respiratory experts. At that appointment I had lung function tests and we discussed trying injections to manage what seemed to be asthma, rather than using inhalers.

The final part of this appointment was a CT scan. The scan showed what looked like cavities in my lungs, which they thought was caused by aspergillus (a condition caused by a type of mould which can affect the lung and cause breathing difficulties). My tests were discussed at an MDT meeting, and I was told that a consultant haematologist who was at the meeting said he wanted to do a biopsy of my lung to rule out malignancy.

When I went back for the results of the biopsy, I was stunned to hear that I had stage 4 classical Hodgkin lymphoma, including in my lungs. It was a bolt out of the blue. Everything went blank and I simply couldn't take anything in. My wife was with me and she asked about 20 questions, but I can't remember one of them.

I was given a book about Hodgkin lymphoma and an appointment was made for me within haematology a week later.

I started to look at the Lymphoma Action and Macmillan websites and read the Lymphoma Action book and gradually things started to make sense. I also read stories of other people who had been diagnosed with Hodgkin lymphoma, which I found really helpful and their experiences kind of settled me a bit. I was going to give it everything!

The consultant explained that I was going to have six cycles of an intensive treatment plan called BEACOPPesc in three week cycles. He explained that it was going to be hard and explained the side effects I was likely to experience. I would feel tired and would lose my hair, all of which happened.

Before starting treatment my dad, my brother and I went to a Turkish barbers and had our hair shaved off and my brother and I removed our beards too. I wanted to take control and saw this as a way of getting the first win over lymphoma.

I was so nervous going into the first round of chemotherapy. I had no idea about how it was administered and I had never thought I would be someone going through this. I went in on Thursday, Friday and Saturday to receive the chemotherapy and the following Tuesday I slept for the first time in 7 months. The cough had completely gone.

For the first three cycles I had no issues, although what was left of my hair fell out pretty quickly. But by cycle 4 I started to get ulcers and by cycles 5 and 6 they were all over my mouth and under my tongue, causing me an enormous amount of pain.

Fatigue crept up on me too and about half way through the cycles it was taking hold and I was falling asleep in the chemotherapy suite. After the second round of chemotherapy I had a PET scan. My doctors said they were really happy with how things were going. I had my final chemotherapy in January 2023 and am gradually building up my strength.

Despite having started a new job just before my diagnosis, my employers have been fantastic and work has been adjusted so I can work when I am able to. In fact, having recently finished treatment, everything seems very strange. My life no longer revolves around treatment, but it doesn't feel back to how it used to be either. My health is so much better than it was back in May 2022. I have lost the cough, I am no longer out of breath, and the asthma that occasionally troubled me seems to have improved too.

I see my experience as a second chance at things; almost like a warning shot. I am re-evaluating what is important and focussing on things that make me and my family happy. It has also been a time of really appreciating what I have in life, like a wonderful family and amazing parents.





# Keeping safe in the sun

**Some treatments for lymphoma can make your skin more sensitive to sunlight (photosensitive) and more at risk of sunburn. This includes radiotherapy, many chemotherapy drugs and some supportive drugs (especially some antibiotics and diuretics).**

It's important to take extra care when spending time outside, especially in the summer months.

Although summer is the time you are most at risk, it is also important to keep safe in the sun throughout the whole year. This means protecting yourself from the effects of ultraviolet (UV) rays which consist of two types of radiation, UVA and UVB.

- **UVA** – this radiation is constant throughout the year and is associated with skin aging.
  - **UVB** – this radiation is strongest during the summer months and is associated with skin burning (sunburn).
- Both types of radiation are always there, wherever you are, even on cloudy days.

Although there are some known benefits of sun exposure, such as increasing vitamin levels, these should be balanced against the known risks.

## How can I protect myself from the sun?

There are a few steps you can take to minimise your risk of being damaged by the sun's radiation. The following tips are aimed to help you stay safe in the sun and are especially important to follow after treatment for lymphoma.

- Keep chemotherapy sites covered in the sun.
- Avoid being in the sun when the rays are at their strongest, between 11am and 3pm.
- Apply a sunscreen with a 'sun protection factor' (SPF) of at least 30. Make sure the sunscreen you use protects you against both UVA and UVB rays. The number of stars on the bottle will tell you how protective it is against UVA rays, and the number on the bottle will tell you how protective it is against UVB rays.
- Wear sunglasses that have a UV light filter to protect your eyes.
- Wear a hat to protect your head and shoulders. If you lost some hair from your head due to lymphoma treatment, take extra care to keep your head out of the sun.
- Use clothing to help protect yourself from the effects of the sun. For example, T-shirts, long-sleeved shirts and trousers can protect the skin on your body.

## Travelling abroad?

Having a lymphoma diagnosis might mean you have some additional things to consider when preparing for a trip outside the UK.

### Travel insurance

Travel insurance helps to cover the costs of things that don't go to plan while you're travelling away from home, like cancelled flights, lost baggage or if you become unwell on the trip.

Insurers will ask questions to work out the cost of the cover.

**It is important that you answer the questions honestly – if you don't tell your insurance company everything they need to know, you might not be covered if you need to make a claim.**

### Healthcare cover (GHIC)

The UK Global Health Insurance Card (GHIC) allows you to get state-provided healthcare in Europe at a reduced cost, or for free. The GHIC card has replaced the European Health Insurance Card (EHIC) for most people.

If you have a current UK EHIC, it will be valid until the expiry date on the card. Once it expires, you'll need to apply for a GHIC – search 'GHIC' at GOV.UK to apply.

**Your GHIC or EHIC is not a substitute for travel insurance.**

### Medication

If you're taking prescribed medicine abroad with you, talk to your GP or clinical nurse specialist at least 8 weeks before you travel. Different countries have different rules about types and quantities of medicine they allow in the country.

Some medication needs to be stored at room temperature (below 25°C). Ask your pharmacist about storing your medicine if you're going to a warm country.

### Travel vaccinations

Check whether there are any specific vaccinations you need to get at least 8 weeks before you travel. Ask your GP for advice about whether you need any, and which are suitable for you.



## A family together but temporarily apart

### **Beverley talks about her son's diagnosis of diffuse large B-cell lymphoma**

I have two sons; my oldest is Ethan and Jensen is three and a half years younger. In 2018, when Jensen was just three, I noticed a change in him. If we went to the park, he didn't want to do anything, and at play gyms he would sit watching the others. He was not getting involved in things and much of the time he would just fall asleep.

Jensen was in pain when he went to the toilet, and it was this that made me take him to the GP. The doctor said it was constipation; despite going back and forth to the doctors for three or four months, there was no improvement.

Jensen was then referred to a specialist and an X-ray was arranged. This indicated that he was constipated, so he was put on Movicol, which seemed to help for a while. But he was losing loads of weight and as his mum I just knew something was seriously wrong.

A follow-up appointment was organised where they did an ultrasound of Jensen's belly which showed thickening of the bowel. The next day his belly became rock hard. I went to the GP and while I was there the hospital rang asking me to go back straightaway.



Jensen was seriously ill. His bowel had started leaking, causing him to have sepsis and severe hypoalbuminaemia (where the level of albumin in the blood is low, which can indicate a disorder of the liver or kidneys).

A biopsy was carried out and we had to wait seven days for the results. In the meantime, they put Jensen on a steroid to try and help as he was now really ill.

In September 2018, Jensen was diagnosed with diffuse large B-cell lymphoma (DLBCL) with the lymphoma blocking his bowel.

Jensen was moved to a children's cancer hospital where treatment with four rounds of COPADM (cyclophosphamide, vincristine, prednisolone, doxorubicin and high-dose methotrexate) was started. The medical team explained that his lymphoma was very fast-growing but that the treatment could usually tackle it.

The next four months were mostly spent in hospital and the chemotherapy was pretty tough. Jensen struggled with horrendous sore mouth (oral mucositis). However, it was noticeable that his stomach was reducing down and he was in less pain. After the third round, it was decided to do a biopsy to check the lymphoma had gone.

The results were discussed with us at a multidisciplinary team meeting (MDT) and it was agreed that they would take out 10cm of his bowel. A scan following the surgery showed no evidence of the lymphoma.

In time, Jensen was back at school and back to himself. After two years we felt we were out of the woods. But in 2021 his poo was not right again. An ultrasound scan was arranged to look at his bowel.

At the time they did not think it would be a relapse of the lymphoma.

In November 2021 some more of Jensen's bowel was removed which revealed he had a whole new B-cell lymphoma. From there, more tests were done which led to them finding a rare genetic immune disorder called X-linked lymphoproliferative disorder (XLP1), which caused both of his lymphomas.

XLP1 is a rare immune condition where an affected person cannot properly regulate the development of natural killer cells (a type of lymphocyte) in response to a viral infection. Children with XLP1 have a greatly increased risk of developing lymphoma and other conditions related to the immune system. Because of this, an allogeneic (donor) stem cell transplant was needed to correct the error in Jensen's immune system.

Donors for allogeneic transplants are often found in siblings, so his brother was tested to see if he was a match. Ethan wasn't a match, so the team had to search further. We were fortunate that there were a few good matches, so work was carried out to identify the most suitable for the donor stem cell transplant.

During this time, Jensen needed to have chemotherapy to keep the lymphoma at bay. He had R-ICE (rituximab, ifosfamide, carboplatin and etoposide) from November 2021 onwards which caused him to have a severe electrolyte imbalance. He then had two more rounds of chemotherapy to bridge him to transplant in June.

This time the treatment experience seemed much tougher for Jensen. Perhaps it was because he was that much older and understood more about what was going on.

Jensen is normally a pretty happy and very chatty boy, but this was making him feel rubbish, and he was fairly down and moody. We could tell how he was feeling by whether he was talking a lot or not.

The transplant was carried out in June 2022 in a specialist transplant hospital two and a half hours from home. He was in isolation for six weeks, so we tried to make it feel homely by putting pictures up on the wall, having lots of sticker books and playing games like Uno, Dobble, Top Trumps and Brainbox. I was very keen for him to keep to a routine, so made sure he got up, had a shower and did a variety of things during the day. The routine really helped, and he managed the treatment pretty well with just a few issues. He developed some viruses, but the team managed to keep on top of things. He also developed a bit of GvHD (graft versus host disease), which fortunately was sorted out.

My husband Jason and I stayed with Jensen during the six weeks isolation. After that, for the next 10 weeks, we stayed close to the hospital as they wanted to see Jensen a couple of times a week.

During that time he did have to go back in a few times as an inpatient with temperature. Jason was back and forth trying to spend time with both our sons.

I worried about how this would affect Ethan. I knew he was being well looked after by my mum and dad, but I could see that he found it much harder this time. He was now 11 and was missing his family being at home. When my parents brought him over to see us he put his hands out to hold mine and his dad's hand. It seemed clear he had really missed us.

Jensen was off school for 14 months as the hospital wanted to wait until the cells were above a certain level. I am still anxious a lot of the time, and I think it's going to take a while before I can feel more confident about Jensen's health; I suspect I will always be anxious about him getting hurt or becoming ill again.

It's been tough for both boys. For Jensen, he has been ill much of the time since he was three. For Ethan he has missed out on time with me, Jason and his brother. But both have done really well.



Jensen, happy to spend time out of hospital with his brother Ethan.



## Take part in our prize draw



Our Prize Draw is back for 2023, with every ticket purchased raising vital funds to support our work.

**Anne has taken part in the Prize Draw for several years – and won 2nd prize in 2022! Here she explains why she likes to take part.**

'In 2017 I'd been feeling unwell for several months but put feeling tired and achy down to my job and thought my night sweats were due to the menopause. As time went on, my symptoms were getting worse and after a range of tests and scans, I received a diagnosis of non-Hodgkin lymphoma.

My first reaction was a mixture of shock and worry. It was a hard time, and I felt overwhelmed trying to process everything. I picked up a Lymphoma Action book at a hospital appointment, and it brought me so much comfort, helping me understand my diagnosis and what will happen next, as well as making it possible for me to have more informed conversations with my medical team. I signed up to receive *Lymphoma Matters* and found it informative and warm and still look forward to receiving it today – it feels like a trusted friend. Lymphoma Action's Helpline Services were also a huge support during this time, as I felt as though I was truly listened to.

***'The information I have been given over the last few years has been invaluable.'***

I like to take part in the Lymphoma Action Prize Draw as it's a way to give something back to a charity that was there for me throughout my treatment, and who continue to be there for me today. I find it a challenge to take part in physical events, so this is an easy and fun way for me to donate. I was delighted to be a winner last year; the prize money funded a trip to Holland to visit my son and grandson.'

To take part in our Prize Draw, please check for a book of tickets with this magazine. Visit our website [lymphoma-action.org.uk/SummerPrize-Draw](https://lymphoma-action.org.uk/SummerPrize-Draw), call the Fundraising Team on **01296 619400** or email [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk)

## Write your Will for free



Don't forget that our free Will service is available to all supporters over the age of 18.

Leaving a gift in your Will is a wonderful way to continue supporting our charity beyond your lifetime. Whatever the size of your gift, your legacy will ensure that we continue to be there and help people live with and beyond lymphoma.

**bequeathed**   
make your Will For Good

Sign up today at [lymphoma-action.org.uk/FreeWill](https://lymphoma-action.org.uk/FreeWill)

## Make your donation worth more - at no extra cost to you - with Gift Aid.

All donations we receive make a huge difference to people affected by lymphoma. If you are a taxpayer, signing up to Gift Aid increases your donation by 25%, meaning that even more people will receive the information and support they need.

Gift Aid is a government scheme that allows charities to reclaim the tax that has already been paid on donations from UK taxpayers. If you choose to Gift Aid, the government will add an extra 25p to every £1 you give to Lymphoma Action.

Research from the Charities Aid foundation found that 23% of eligible donors don't use Gift Aid, meaning charities like us miss out on thousands of pounds each year.

It's a really simple and effective way to give more, at no extra cost. If you haven't already made a Gift Aid declaration for us, increase your donation today. Just email [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk) or call **01296 619400**.

*giftaid it*

# Highlights from ASH

In January we attended a conference which presented the highlights of the American Society of Haematology's 64th Annual Meeting. Clinical experts described some of the latest developments in haematology.

Professor Christopher Fox, Consultant Haematologist at Nottingham University Hospitals, chaired an afternoon session which showcased the exciting research taking place in all areas of lymphoma. The meeting highlighted how active and passionate the lymphoma research community is, with many promising new treatment options in the pipeline.

## Lymphoma biology

**Dr Jessica Okosun, Barts Cancer Institute, London.**

Understanding the biology of lymphoma can inform many areas of diagnostics and treatment. Current research is asking:

- Can the microenvironment of lymphoma predict treatment outcomes? Studies in diffuse large B-cell lymphoma (DLBCL) show that this is a complex area but that this could be used in the future to help guide therapy selection.
- Can biomarkers in the blood help predict who will respond to treatment?

Analysing data from clinical trials could help guide who will benefit from new immunotherapies such as CAR T-cell therapy.

- Can biomarkers be used to assess treatment success? The use of a biomarker called 'ctDNA' to predict who is likely to relapse after treatment could be seen in clinical practice soon.

## Chronic lymphocytic leukaemia (CLL)

**Dr Piers Patten, King's College London**

Clinical trials remain an important option for people with CLL. Two new therapy areas undergoing clinical trials are:

- Doublet therapy. Results from the **GLOW** and **CAPTIVATE trials** indicate promising results following treatment with both ibrutinib, a BTK inhibitor, and venetoclax, a BCL-2 inhibitor. The FLAIR trial remains open looking at whether those with high-risk genetic changes benefit from this doublet treatment.

- Covalent BTK inhibitors. The randomised, phase 3 **ALPINE trial** suggests that zanabrutinib, a next generation BTK inhibitor, gives better results than ibrutinib for relapsed and refractory CLL.

## Mantle cell lymphoma (MCL) and low-grade lymphoma

**Dr Toby Eyre, Oxford University Hospitals**

Results from the **TRIANGLE trial** indicate that adding ibrutinib, a BTK inhibitor, to the standard treatment option (chemo-immunotherapy followed by autologous stem cell transplant (ASCT) and rituximab maintenance therapy) can improve outcomes for people with MCL. The study also questions the need for ASCT in this treatment regimen, potentially allowing those with MCL to avoid the associated toxicity. Data analysis is ongoing.

The **BRUIN trial** is studying a drug called pirtobrutinib, a reversible BTK inhibitor, in people with relapsed or refractory non-Hodgkin lymphoma. Latest analyses indicate high treatment response rates and a favourable safety profile for those with MCL or Waldenström's macroglobulinaemia.

Twelve years of follow up in the '**Watch & Wait**' trial indicates that rituximab monotherapy for asymptomatic follicular lymphoma patients may extend the time before additional treatment is required.

## High-grade and CNS lymphomas

**Dr Wendy Osborne, NCCC, Newcastle**

A number of trials have focussed on whether we can improve on the standard treatment option of R-CHOP for diffuse large B-cell lymphoma (DLBCL).

- The **REMoDL-B trial** indicates that adding bortezomib, a proteasome inhibitor, to R-CHOP can improve outcomes for patients with 'activated B-cell' type DLBCL. This suggests that gene expression profiling may be important to determine individual treatment choice.
- The **POLARIX trial** shows that treatment with polatuzumab vedotin, an antibody-drug conjugate, and R-CHP improves outcomes compared with R-CHOP for people with previously untreated DLBCL. This treatment is now available in the UK.

Analysis of data from multiple trials indicates that a more intensive treatment regimen, giving chemo-immunotherapy every 14 days (R-CHOP14), improves treatment outcomes for primary mediastinal large B-cell lymphoma (PMBCL) compared to the standard regimen of every 21 days (R-CHOP21).

Research has focussed on the use of CAR-T cell therapy for relapsed disease:

- The **TRANSFORM trial** indicates that CAR-T cell therapy may give beneficial outcomes over standard treatment options for early relapsing large B-Cell lymphoma (LBCL).
- Data analysis from previous trials shows that LBCL patients treated with bendamustine-containing regimens in the previous 9 months have lower response rates following CAR-T cell therapy. This indicates that therapy selection must take into account previous treatments.

Research confirms that autologous (self) stem cell transplant (SCT) is still an important component of central nervous system (CNS) lymphoma treatment in young fit patients.

Autologous SCT should also be considered for older patients with results from the **MARTA trial** showing similar survival rates to those seen in younger patients.

## Hodgkin lymphoma (HL)

**Professor Graham Collins, Oxford University Hospital**

For advanced stage classical HL:

- Early results from the **HD21 study** show a reduction in treatment-related side effects with BrECADD (a treatment regimen including brentuximab vedotin, an antibody-drug conjugate) compared to eBEACOPP (the standard chemotherapy regimen). This trial is ongoing.
- Long term follow-up of the **RATHL study** supports the use of an interim PET-CT scan after 2 cycles of treatment to guide further treatment. Omitting bleomycin from the treatment regimen in people with a negative interim scan did not impact patient outcomes.

Checkpoint inhibitors, a type of immunotherapy, have been a focus of research:

- The phase II **NIV AHL trial** confirms the efficacy and safety of nivolumab-based treatment of early-stage HL. Future trials will take this further, with the **INDIE trial** investigating a chemotherapy-and radiotherapy-free 1st-line HL treatment in optimally responding patients.
- The **NICE trial** shows promising results for nivolumab as a treatment for refractory and relapsed HL.
- Adding favezelimab, a LAG3 inhibitor, is a promising approach to treatment for those with relapsed HL following prior checkpoint inhibitor treatment (**MK-4280-003 study**).

*With thanks to Dr Jessica Okosun, Dr Piers Patten, Dr Toby Eyre, Dr Wendy Osborne and Professor Graham Collins.*

## Primary central nervous system lymphoma (PCNSL)

**Dr Edward Poynton, Dr Arun Jha, David Howarth and Professor Chris Fox**

PCNSL is a fast-growing B-cell non-Hodgkin lymphoma which affects the brain and central nervous system. There are currently two clinical trials available to patients in the UK, investigating new and modified treatments aiming to improve outcomes for people affected by this rare lymphoma.

### OptiMATE: A phase III trial for patients with newly diagnosed PCNSL

Many patients are currently treated with a chemo-immunotherapy protocol called MATRix which can be very effective but can also cause severe side effects and risks for some patients. The OptiMATE trial aims to reduce the intensity and duration of MATRix treatment while improving rates of remission and survival for patients with newly diagnosed PCNSL.

### PRIZM+: A trial for patients with previously treated PCNSL

This trial investigates a targeted treatment (zanubrutinib) in people whose PCNSL did not respond to, or relapsed following, initial treatment with standard chemotherapy. Zanubrutinib blocks important cell signalling pathways and has been shown to be effective in other types of B-cell lymphoma.

### Could you provide a patient perspective?

The team running these clinical trials is looking for people with experience of PCNSL to become public contributors. These contributors help to give a patient's perspective to the way trials are run and help review and enhance patient-facing documents. If you would like to get involved, please contact Hannah Taylor at [consumers@ncri.org.uk](mailto:consumers@ncri.org.uk)



## Top Tips: looking and feeling good

Treatment for lymphoma can have side effects. These side effects vary depending on the treatment and how you react to it, but some can affect physical appearance. Although they are often temporary, side effects can have a big impact on how we look, and how we feel about ourselves.

We asked members of our Facebook group for their 'top tips' and suggestions for looking and feeling good, particularly during and after treatment.

*Thanks to everyone for their ideas.*

### Coping with hair loss

- It's a shock to learn that some treatments cause you to lose your hair but I found it really helped to donate it to Little Princess Trust. Knowing that I wasn't losing it, I was giving it away to help a child in need really helped me accept making the shave without too much hardship.
- If you are going to lose your hair consider getting it cut short before treatment starts. Wearing a beanie hat if your hair starts falling means it doesn't go everywhere.
- I didn't opt for a wig but invested in bright scarves and cheap statement earrings to wear with loungewear - a very bohemian look. There are lots of tips for tying scarves online.
- After not getting on with a wig, I found some really glamorous headscarves that had a tie scarf. That felt a bit old-school Hollywood to me.
- I found bamboo headscarves super comfy and stylish – I felt good wearing them.
- The turban hats look good and are soft and cozy.
- Getting headwear or wigs before treatment means you can get used to them. Many hospitals have a wig bank so you might like to ask your medical team about this.
- When your hair starts to grow back it can be an opportunity to experiment with new styles - maybe you don't want your old hair back?! I've kept mine short and dyed it pink since it grew back a year ago and I've never been happier with it.
- I've kept my hair short. Most of my curls have now gone but I much prefer my short cut. I would probably never have been brave enough to give it a try before.



## What to wear

- Think about treating yourself to some pretty, warm outfits that you can lounge around in and use for hospital visits.
- Even if you don't feel like it, it can help to make an effort to get dressed everyday. Some cheerful loungewear and nice underwear can feel really good.

## Teeth, skin, makeup and nails

- Get any dental work and check-ups done before your treatment starts. Get some new toothbrushes and non-alcohol based mouthwash.
- My skin became so sensitive during treatment and my scalp was very dry and itchy so I used calendula face cream and calendula baby oil on my scalp.
- I kept my skin routine very basic as my skin started reacting to chemotherapy. Gentle cleansers, hyaluronic acid serum to increase hydration, moisturiser with vitamin C to boost the skin with antioxidants and an SPF 50.
- Avoid harsh or scented skin products with ingredients that can irritate skin.
- Sometimes it's best to avoid using your favourite products during treatment as you may be put off them in the future because of the association with treatment.
- Try to moisturise your skin and get some nice foot products to indulge in a home foot spa from time to time.
- Experiment with makeup. Eyebrow pencil can be your best friend. If your lashes fall out, a soft brown eyeliner (I used shadow on a thin brush) can look less harsh and more flattering than black eyeliner. Some cosmetics counters have free makeup and advice services for people going through cancer treatment (check online or in-store).
- I took part in the Look Good Feel Better nail class and picked up some amazing tips. I started using nail hardener, cuticle oil, applying black nail varnish on chemo treatment days to limit further damage. I prioritised using handcream on my hands which had become dry and sensitive through treatment and constant hand washing and sanitising.

## Day to day

- It's good to do things that make you feel like you still have some control of your body.
- Getting outside for a walk or a 10-minute yoga stretch on the floor can help if you feel like you have no energy.
- Playing my favourite music fairly loud is great or just watching TV.
- Top up your devices with books or download box sets that you can lose yourself in. It is something to do when having chemo, waiting at appointments or when sleeping is difficult.
- Staying connected with others on Facebook or chatting on the phone really helps.
- Drinking water keeps you hydrated. Buying some cheap fancy new drinking glasses means that the chore of drinking fluids feels more like an occasion than an ordeal. Using lovely champagne flutes and spirit tumblers with ice and fruit slices helped me enormously.
- Follow your emotions: cry if you need to, rant if you want to, talk if it helps, don't be frightened to ask for support and laugh as much as you can.

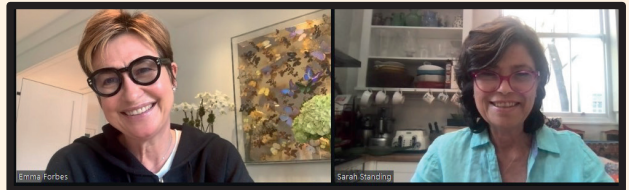
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# Celebrating our incredible volunteers

On 5 June, our virtual Volunteer Recognition event returned for its second year to recognise the achievements of our wonderful volunteer community.

Our annual event celebrates the invaluable time, skills and expertise volunteers give to our charity, and the impact they make on the lives of people affected by lymphoma.

We were delighted to be joined by fantastic hosts journalist and author Sarah Standing and broadcaster Emma Forbes. They presented our 23 awards for length of service, and seven for outstanding contributions.



*“To be able to support and recognise those who volunteer their time and skills to Lymphoma Action is an honour. Having received treatment for non-Hodgkin lymphoma myself, this is a charity very close to my heart as I have seen first-hand what a comforting hand it holds out to people affected by lymphoma and their families.”*

*Evening host, Sarah Standing*

Many of the volunteers told us how much they value their volunteering and being part of the Lymphoma Action team, like Melinda who was awarded commendation for Outstanding Contribution: “I was really shocked to receive the award, in the best way possible. I really love everything I do through my volunteering so this award means a lot to me, more than I can say. Thank you so much.”

“It was a privilege to share the difference our volunteers make throughout the evening and present our volunteer awards,” says Carly Benton, Volunteering Development Manager. “Volunteers are at the heart of our work, and they make many of our services and activities possible. We are always so inspired by their kindness and generosity.”



There are many ways you can join our volunteer community and help us face lymphoma together.

Get in touch at

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

or email us at

[volunteering@lymphoma-action.org.uk](mailto:volunteering@lymphoma-action.org.uk)

## Seeking Buddy volunteers

Our Buddy Service offers people the opportunity to talk one-to-one with someone with similar experiences to them. Closely matching people with a trained volunteer, Buddies offer understanding, sharing of experiences and a listening ear.



Although our Buddies have a wealth of experience, we are looking to widen the reach of the service with new Buddies with specific types of lymphoma:

- low-grade non-Hodgkin lymphoma without treatment (active monitoring)
- CLL and SLL
- marginal zone lymphoma
- Waldenström's macroglobulinaemia
- skin lymphoma
- mantle cell lymphoma
- T-cell lymphoma
- stem cell transplant (Hodgkin lymphoma)
- NLPHL
- CNS lymphoma
- rare lymphomas (double-hit, grey zone).

We are also looking for individuals with experiences of transformation, antibody therapies, CAR T-cell therapy, young adults, partners, carers and relatives.

If you'd like to know more please call the helpline, or to see our complete list of experiences or register your interest see [lymphoma-action.org.uk/BecomeABuddy](https://lymphoma-action.org.uk/BecomeABuddy)

## 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/online-support-meetings](https://lymphoma-action.org.uk/online-support-meetings)



let's talk  
lymphoma

LET'S GO

# September, we've got this!

Join us for Blood Cancer Awareness Month  
and help us get the conversation started.

Get involved by talking lymphoma in your community,  
telling your lymphoma story or taking on one of our  
exciting challenges.

To find out more and to request your pack, simply scan  
the QR code below, visit [lymphoma-action.org.uk/LetsTalk](https://lymphoma-action.org.uk/LetsTalk)  
or call 01296 619400.



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