

lymphoma matters

ISSUE 123

SUMMER 2022



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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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With thanks to Incyte Biosciences UK Ltd and Takeda for funding this issue of *Lymphoma Matters*. As per our policy, they have no influence over our content.



Ropinder Gill
Chief Executive

Do you know how
clinical trials started?
Find out more on
page 23.



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

Moving forward

Summer is now here and we can look forward to a touch of nice weather. The sun was definitely shining on the day of our Bridges event. It was really something; not just because of the amazing generosity of everyone who sponsored our walkers, but because this was our first hybrid event since the start of the pandemic. We were overwhelmed by how many people took part around the UK and how many wanted to make the journey into the capital.

Another inspiring event that has recently taken place was our Volunteer Recognition Awards. It was terrific to be able to bring so many volunteers together, albeit virtually, with many of them having supported us for more than 15 years. It was also an opportunity to reflect on the breadth of volunteering opportunities, both virtual and face-to-face, all helping to make a real difference to people affected by lymphoma.

It's not just supporters who are doing more face-to-face. Our head office is busier as we work in a more flexible way, recognising that we can be productive at home, but also need our office environment to work to the best of our abilities for you.

As part of our new working practises we are moving to smaller, but better suited, new offices following the end of our lease this year. We're excited that by the time you read this we should be celebrating our move to Bell Business Park, which is still in Aylesbury. We hope to give staff what they need to be able to work well, whilst also supporting them to have a good work/life balance and focus on what we are trying to achieve.

You can read about our work and achievements from last year in our latest annual accounts at lymphoma-action.org.uk/Accounts2021

Thank you for your continued support.

Ropinder Gill
Chief Executive

Mark Harrison appointed as new Chair of Trustees

Mark Harrison officially became our Chair of Trustees on 9 May – taking over from Gordon Johns. Mark joined the Lymphoma Action Board ten years ago, so brings an invaluable understanding of our culture and values.

Mark comments: 'I was first drawn to Lymphoma Action after my father was diagnosed with chronic lymphocytic leukaemia (CLL) in 2010. Lymphoma Action was making a real and tangible difference to many people, including my family, with unwavering support and commitment.'



'I get a lot of personal satisfaction being involved with Lymphoma Action and feel privileged to be taking on this role at an incredibly exciting time for the Charity.'

Taking the lead for 10 years

Gordon Johns has stepped down as Chair of Board of Trustees for Lymphoma Action after ten years in the role. During his time as Chairman, Gordon has overseen the drive to improve the Charity's online information, a re-brand and the roll out of Live your Life self-management workshops. Most recently, he has supported the organisation through all of the challenges of COVID-19.

'I think Lymphoma Action is in the strongest position it's ever been' says Gordon, 'which is exactly why it's the right time for a change.'

'The Chair of Trustees has the crucial role of setting the tone for the whole Board. It's a credit to Gordon that the Trustees have such a good relationship and work so effectively together. He has always been really committed to bringing out the best in the Charity and its employees' says Ropinder Gill, Chief Executive at Lymphoma Action.

'We appreciate all the time and energy Gordon has dedicated to us over the years and wish him all the best for the future.'



Proud to be the patient voice

Before any new medicine, treatment, medical device, diagnostic technique, vaccine procedure or system is available through the NHS, it goes through an evaluation called a health technology appraisal (HTA). This process assesses how well the treatment works and also considers its cost effectiveness.

HTAs are carried out by the National Institute for Health and Care Excellence (NICE) for England, with Wales and Northern Ireland usually following the NICE guidance. Scotland follows a different process, run by the Scottish Medicines Consortium (SMC). An HTA involves clinical stakeholders (such as medical professionals), patient stakeholders (such as Lymphoma Action), the drug company that makes the new technology and representatives of independent health economic groups (who do an independent economic assessment).

Lymphoma Action are invited to represent the patient voice at all HTAs that are related to blood cancer and respond to those that affect people with lymphoma. By representing people affected by lymphoma, Lymphoma Action strives to put the patient voice front and centre of this incredibly important process. Find out more about HTAs and how Lymphoma Action are involved at lymphoma-action.org.uk/HTA

Take part in our Summer Prize Draw



Many people will have a book of prize draw tickets with their magazine. Our Summer Prize Draw is an essential way for us to raise funds to deliver the services which truly make a difference. We are here for those affected by lymphoma, for their family, friends and carers and also for the amazing healthcare professionals working on the frontline.

Advanced Nurse Practitioner Charlotte Bloodworth says 'As a specialist nurse responsible for giving information and support to people who have been diagnosed with lymphoma, Lymphoma Action is absolutely essential to my practice. With them, I have so much more support to offer. In an age where we have so much information available, it's so important to me to direct people to the best information, and for me, this is Lymphoma Action.'

The Prize Draw is a great way for you to help support our services and make a difference to people living with a lymphoma diagnosis. Every ticket brought helps to ensure no one has to face lymphoma alone. Please visit lymphoma-action.org.uk/SummerPrizeDraw to buy your tickets or find out more. Alternatively call the Fundraising Team on **01296 614419** or mail fundraising@lymphoma-action.org.uk



The role of the MDT

We recently held a webinar to look at the role of the multi-disciplinary team (MDT) meeting. Here is a summary of the webinar, where Professor John Radford was joined by Consultant Haematopathologist Dr Bridget Wilkins, Advanced Nurse Practitioner Anya Aspinall and Occupational Therapist Jennifer Woods.

What is a multi-disciplinary team meeting?

Multi-disciplinary team (MDT) meetings bring together a team of key healthcare professionals who help direct and coordinate the care of people on the cancer pathway.

For lymphoma, the MDT is made up of:

- haematologists and/or medical oncologists, with clinical experience and expertise in treating lymphoma with chemotherapy, transplantation and cellular therapies
- clinical oncologists, who also have clinical experience in lymphoma and in addition advise about the use of radiotherapy
- radiologists, who review and report scans and X-rays
- histopathologists, who examine tissue samples to confirm diagnosis
- clinical nurse specialists (CNS), who have day-to-day contact with patients through diagnosis, treatment and care
- additional allied professionals as needed, such as occupational therapists, physiotherapists and social workers.

In 2000, MDTs were accepted as part of the National Cancer Plan and have become the gold standard for treating and managing cancer, ensuring consistency of care across the country. Every person affected by lymphoma, wherever they live in the country, should have their care discussed and planned at a central MDT meeting.

MDT meetings mean a holistic approach is possible, with professionals from different disciplines coming together to represent the person affected by lymphoma from different perspectives. The MDT discusses and develops a plan that is relevant to that individual and appropriate for their circumstances. This discussion may also include new approaches or clinical trials.

The plan considers factors including:

- the pathological features of the lymphoma including routine microscopy and the results of special tests
- the results of imaging such as CT, PET and MRI scans

- the person's specific circumstances, such as how close they live to the hospital, whether they work or have young children to look after
- any other issues, such as heart disease or diabetes, or difficulties that mean mobility might be a problem
- the availability of relevant clinical trials.

Do all hospitals have MDTs?

MDTs are concentrated in cancer centres and regional centres of excellence, so that a wide variety of expertise can be drawn upon. District general hospitals, for example, are still able to access this broad knowledge, often by attending the meeting in person or remotely.

How many cases are discussed at an MDT meeting?

The number of cases discussed at an MDT meeting can vary significantly. The meeting may have a list of 10 to 25 people to discuss and enough time needs to be devoted to each person. Cases can vary significantly; some are fairly straightforward, and others are very complex. It is important that everyone is able to contribute to the discussion and put their views across. Although people with lymphoma cannot attend an MDT, they can discuss specific wishes or concerns with their CNS beforehand.

To what extent are MDTs important to the diagnosis of lymphoma?

Histopathologists are core members of the MDT. They will have spent a lot of time before the meeting making an initial diagnostic assessment from samples taken and reviewing these in preparation for the meeting. It is not always possible to make a clear diagnosis, and this is where the histopathologist will help the team make a pragmatic decision.

In these cases, it can be really valuable to be in the MDT meeting with other experts to discuss any concerns and consider whether additional tests would be helpful. Although it is rare for this to happen, it is a very important use of the MDT meetings.

Is everyone with lymphoma discussed at an MDT meeting and at what points?

There are time points along the pathway where people are discussed during MDT meetings. Almost all cases will be discussed at diagnosis with more complex cases likely to be discussed at the other points too.

- At diagnosis, MDT meetings include the histopathologist reviewing the diagnostic material and the radiologist reviewing the scans (CT or PET). At this meeting a diagnosis is made, the staging confirmed and a treatment pathway and/or package of care is agreed upon.
- In some cases, the MDT meeting includes a discussion about a person's interim scan.
- At the end of planned treatment, MDT meetings might discuss the results of imaging and scans if there are questions about the need for further treatment.
- At other times the results of scans or other investigations might be discussed if there are concerns about the possibility of recurrent disease or there is a need for a new biopsy.

The fact that someone is only discussed at one MDT does not mean they are less important. It simply means they have a clear diagnosis, a clear course of recommended treatment and the decisions are agreed upon and fairly clear.

How often do MDT meetings take place?

In some hospitals, MDT meetings might occur once a week, although in many places they happen more often than that.

Although MDT meetings are the focus of discussion, it is not the only time an individual is discussed, and a lot of work is done before the meeting. A lot of communication will occur between different teams, for example to organise tests, scans and biopsies.

Will the person be told about the outcome of the MDT meeting?

When the MDT meeting has come to a conclusion, a member of the clinical team will discuss the outcome of the meeting with the person affected by lymphoma to see whether the plan is acceptable and reasonable. In some cases, there might be a number of options available, and these can be explained and discussed.

Who represents the individual at an MDT meeting?

The clinical nurse specialist (CNS) is usually the person who shares additional information about the individual and represents their wishes. They are in regular contact with people affected by lymphoma either in clinics, during treatments, on the wards or by phone. CNSs encourage people to let them know if they have any problems, such as any side effects they might be experiencing.

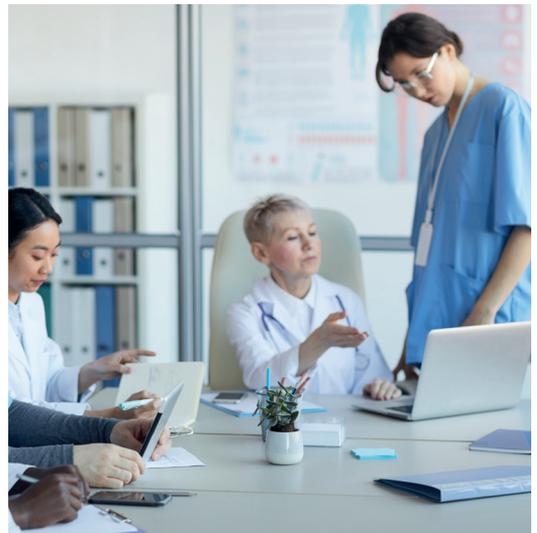
If someone is struggling with treatment, it is likely to be the CNS who raises this issue in MDT meetings. Steps can then be put in place to help them, such as implementing physiotherapy or occupational therapy. There are things that can be tried to make it easier for people to manage any side effects of treatment. Despite these efforts, treatments sometimes need to be changed or stopped. These conversations come from the individuals through the CNS and are often discussed at MDT meetings.

Why is it that MDT meetings are so important for patient care?

The MDT meetings bring together high-quality expertise; this includes histopathology, imaging, clinical knowledge and experience of managing lymphoma. In addition, allied healthcare professionals can be brought in to discuss other elements of an individual's care. All of this is critically important and the MDT brings it together and formalises it in a way that didn't happen before. Previously, the quality of care depended on who you saw; now it depends much more on the group as a whole, which means that the standard is consistently high.

A cancer pathway can be complex and really disjointed and may involve multiple agencies and often multiple hospital sites. The MDT brings it all together, enhancing cohesion and good communication between all the professionals involved.

It is also really reassuring for individuals to know they are part of a cancer pathway coordinated by the MDT, whose sole purpose is to make sure their care is optimised and as effective as it can be.



What difference does the MDT make to the members of the MDT?

Healthcare professionals feel more part of a clinical team as a result of the MDT meetings and contribute better to the overall discussion. The MDT enables shared decision-making in a forum where information from different key areas is available. But the real purpose of the MDT meetings is to improve outcomes and standard of care for people affected by lymphoma.

Can I attend my own MDT?

Individuals are not able to attend the MDT meeting, but they should feel reassured that decisions made about their diagnosis and care will be shared with them in the clinic or by phone afterwards. If there is information the individual would like raised at the MDT meeting, such as treatment concerns or wishes, then talking to their CNS before the planned meeting is the best place to start.

The MDT is not a secret meeting where healthcare professionals want to keep things from people. To put it in context, the MDT looks at lots of cases and there isn't the time and infrastructure to accommodate individuals as well as maintain confidentiality around other cases discussed.

Will waiting for an MDT mean my diagnosis or treatment is delayed?

If someone is very unwell and they need to start treatment urgently, then it will be started. Clinicians have experience in knowing what to do in these circumstances, and whilst the MDT meeting is a way of endorsing that and making sure everything relevant has been considered, treatment will not be delayed.

The people who make up the MDT are all communicating and accessible whatever day of the week or time of day it is, so in some cases, information can be gathered and discussed and plans made outside the MDT meeting.

If the MDT decides on a particular course of action, can I disagree with it?

The MDT does not tell people what to do and does not force someone to follow their suggested plan. However, a lot of discussion has gone into the decision, and people should feel confident that it is considered the best course of action.

This is about shared decision making and if a person does not agree with the outcome, or wants more information, it is OK to ask all the questions they want or ask for a second opinion. In many cases, people think about it at home, discussing it with family, friends or their GP.

Having a second opinion and having a discussion in a different way can give a new perspective, and can help to reassure people that it is the right decision for them.

This information is based on a webinar that took place in April 2022. You can watch the unedited webinar at lymphoma-action.org.uk/MDT

With thanks to Professor John Radford, Professor of Medical Oncology and Director of Research, The Christie NHS Foundation Trust, Manchester for reviewing this summary.

September is Blood Cancer Awareness Month – get involved

Blood Cancer Awareness Month takes place every September.

Why not take part this year and raise the profile of lymphoma, the fifth most common cancer? Together we can make even more people aware of the signs and symptoms, and there are lots of ways to get involved.

With one person in the UK diagnosed with lymphoma every 27 minutes, we've put together a big 27 in 27 fundraising pack, with a whole heap of fundraising ideas you can do throughout Blood Cancer Awareness Month. Here are just a few ideas:

- **bake and sell 27 cupcakes at home, school or work**
- **hold a raffle with 27 prizes**
- **do 27 squats, star jumps or press-ups each day**
- **walk your dog in a Lymphoma Action bandana for 27 days (they're eye-catching and will spread the word!)**
- **get family and friends to sponsor the kids to do 27 chores**
.... and don't forget to share our social media posts as well as creating your own!

Get in touch for your 27 in 27 pack and let us know what you'd like to do! Email fundraising@lymphoma-action.org.uk, call the team on **01296 619400**, or grab your pack from our website at lymphoma-action.org.uk/27in27



Go purple on 15 September for World Lymphoma Day



World Lymphoma Day is on Thursday 15 September and we would love you to go purple for the day to raise awareness of lymphoma! We have created a fabulous 'purple pack' for you to give you some ideas. To get your pack, call **01296 619400**, email fundraising@lymphoma-action.org.uk, or visit lymphoma-action.org.uk/world-lymphoma-day

A huge thank you!...

...to all our wonderful fundraisers who have raised money for our charity up and down the country in recent months. Here are just a few.

Six talented young fundraisers – Felix, Poppy, Ava, Thea, Esme and Freya – donned their dancing shoes for a 5-hour danceathon to 'put a smile on the face of their family friend who is going through treatment for lymphoma', raising a fantastic £3,450!



Alison, who was diagnosed with Hodgkin Lymphoma on 27 May 2020 and, having finished her treatment and doing well, decided to turn 27 May into a happier occasion by baking and raffling her amazing cake creations, raising over £1,700.

The doggies of Dora's Doggy Daycare (and their humans) held a doggy first aid day and went on a sponsored walk to raise money in support of Kate's skydive. Kate's big jump was to raise money in memory of her dear dad, Tony. We are so grateful to Kate and her doggy companions for raising a wonderful £2,845.





Learning to adapt to an incurable but manageable lymphoma

Nicola talks about her experience of follicular lymphoma.

I had recently had a baby daughter; a sister for our 7-year-old son Archie. I work as a social worker for adults with physical disabilities and was returning to work after maternity leave. I had only been back in the office for half a day, when we were all sent home because of the pandemic.

In May 2020 I noticed I was having difficulty swallowing. I was having a drink of water in bed and thought it was going down the wrong way. This happened several times over the coming days. I also had a sore throat and a cough, but tests for COVID-19 came back negative.

It was progressively getting worse and when I was driving I noticed that if I turned my head to the right it really affected my breathing, almost like something was blocking my windpipe. In August I called my doctor.

My doctor organised a two-week referral to a thyroid specialist who arranged an ultrasound of my neck. A lump attached to my thyroid and another lump in front of it were visible on the scan. At first it was suggested that these were likely to be goitres, but a fine needle biopsy was organised and in November 2020 I had an ultrasound guided fine needle biopsy.

The process involved them removing a sample from one of my parotid glands (salivary glands that sit just in front of the ears on each side of the face).

The biopsy results came back as benign (non-cancerous) and they suggested a follow-up appointment in six months' time. Although it was benign, it was still causing problems for me. By the end of January I was struggling to talk and my voice had completely changed. In addition, where they had taken the biopsy, a painful lump had appeared.

I went back to my GP who thought it could be a blocked salivary gland and started me on a course of antibiotics, which did not improve things. I ended up in A&E where an ENT consultant also thought it looked like a blocked salivary gland. He tried to squeeze the lump to clear it and I almost hit the ceiling with pain. A core biopsy of the parotid gland was arranged and a week later I had an appointment to meet with a consultant.

I was told that the biopsy had shown that I had follicular lymphoma and that I would be referred to haematology.

Despite only being 33, it wasn't a shock in the end as it was obvious to me that something was very wrong. Over the last few months, I had been doing a lot of my own research, so I knew a little bit about lymphoma.

The next week was difficult. My children were an absolute blessing as they took my mind off what was happening. But when they were asleep I spent time doing lots of reading. I had been given the Lymphoma Action *Low-grade non-Hodgkin lymphoma* book by my medical team.

The book gave me specific information about my condition, and having searched the Lymphoma Action website as well, I felt more reassured.

I had a full body CT scan and further biopsies in my neck. This confirmed that the lumps in my neck were lymphoma, and the scan found a tumour in my right pelvic socket, my abdomen (belly) and the mesentery (a fold of membrane that attaches the intestine to the abdominal wall).

The lump in my neck had pushed my gullet (where food passes from the mouth to the stomach) over to the right of my neck and so they needed to start treatment straightaway. I was to be treated with chemotherapy and immunotherapy; six courses of bendamustine and obinituzumab.

I told the children that I was likely to be ill and that I might lose my hair. What I hadn't appreciated was that with this regime I wouldn't actually lose my hair.

Certainly to start with, it was the steroids that had the most noticeable effect. I was absolutely 'wired' and then crashed. I also found I couldn't sleep, so quickly became exhausted. But in truth I found that I was coping really well with the treatment, to the point that in the early days I asked the nurse whether it was normal to feel this OK.

However, for me the treatment had a cumulative effect. The side effects started with a bit of nausea, but that developed into severe sickness, as well as constipation and diarrhoea. I also had quite a bit of pain in the tops of my legs and my knees which has improved but I can still feel. I also had days when I felt so exhausted, I didn't want to move.

My mid-point scan after the third round of treatment showed that I had an excellent response to treatment with the lymphoma having significantly shrunk. The lump on the side of my face was no longer visible, which was reassuring, although the CT scan showed a small lump still on my thyroid.

I finished treatment in September 2021 and have started maintenance therapy, having an infusion of an immunotherapy treatment called obinutuzumab every 8 weeks, which I am due to have for two years.

During treatment I was overwhelmed by the number of calls and texts asking how I was doing. I was happy that people cared, but was struggling to keep up with the conversations, and started to worry that I wasn't replying to everybody. I therefore decided to set up an Instagram page so that I could post updates on there. A bit of a community built up around Instagram, and one of the main topics of discussion was around 'remission'.

I know that follicular lymphoma is incurable and know it will come back again. However, I became fixated on reaching remission. I asked my consultant whether he would say I was in remission. His response was that because of the nature of my lymphoma, he wouldn't use the term 'remission'.

That set me back a bit, but I slowly came to terms with the fact that I am facing a condition that is manageable but not curable. It has taken me some time to adjust to this being my new life; my new normal. A life that includes regular hospital checks, blood tests and treatment. At first this felt overwhelming, but I am learning to accept it. I'm not quite there yet, but hopefully this is something I will come to terms with, and learn not to think about it much of the time.

I did have six sessions with a counsellor via BUPA following the end of treatment. I had been worried about the 'stigma' surrounding mental health and the fact that I felt I needed some counselling, but these sessions helped me massively. I would recommend counselling to anyone going through cancer treatment and people shouldn't hesitate to ask for help if they need it. I wish I had done that sooner.

One of the main things that affected me was that I am a social worker, whose job is to help others, but who then became the person on the receiving end of such assessments and support. I'd just never imagined I would be that person on the receiving end, and especially not at 33 years old.

I returned to work in February, which for me was an important part of my recovery. I had a meeting with occupational health who said that I would need to work from home for the next two years as I was on maintenance therapy. At first I was disappointed with this, being a social worker who cannot see people, but I understand that they are doing it to protect me. In fact, I am finding it works much better than I would have thought and am enjoying being back in the workplace.



£43,847 and rising . . .

Well done to all those who took part in our flagship event Bridges of London and Britain, which took place on Sunday 22 May. It was fabulous to see a wave of purple T-shirts zigzagging their way across the London bridges in the sunshine. That was replicated across the country with people walking in their own towns and cities. Your fundraising will make a massive difference to those affected by lymphoma, so from everyone at Lymphoma Action we send you all a heartfelt thank you!



Top Tips: healthy eating (even when you don't feel like it)



Eating a healthy diet is important for both physical and mental wellbeing. It gives your body the nutrients it needs to grow, repair and work well.

By staying in good general health, more treatment options could be available to you. It can also help you tolerate chemotherapy and protect you from infection.

It's important to continue to eat well after your treatment to help in your recovery too. Getting the nutrients you need helps to keep your strength and energy up, and can lower the risk of developing other cancers and illnesses.

We asked our Facebook group and online support meeting members to share their best tips around eating. *Thanks to everyone for their ideas.*

Eating and drinking when your mouth is sore

- Ice lollies
- Yogurts, custard and trifles
- Milkshakes with ice cream
- Water melon pieces
- Liquid complete meals
- Let hot food cool a little
- Mashed potato
- Scrambled eggs
- Rice pudding
- Noodles or pasta
- Porridge
- Soup – it can be bland or seasoned to whatever your taste

When you feel nauseous

- Ginger biscuits
- Ginger and lemon tea
- Ginger sweets to suck
- Dry biscuits – like rich tea
- Cream crackers
- Rice cakes
- Boiled potatoes
- Plain rice
- Ready salted crisps
- Ice lollies
- Toast – its all I managed for a few days
- Cornflakes

Eating to put weight on

- Add cream to porridge, sauces and mash
- Add cream to soup
- Add butter and cheese to scrambled eggs or potatoes
- Add milk powder to drinks
- Protein shakes using full fat milk
- Spoil yourself – have a chocolate biscuit!

When everything tastes bad

- Frozen grapes or pineapple
- Lucozade
- Ginger beer
- Earl grey tea - I didn't fancy my usual cuppa
- Lemon barley water or sweets
- Anything with a strong taste – crisps, strong cheese, ginger nuts and spicy curry

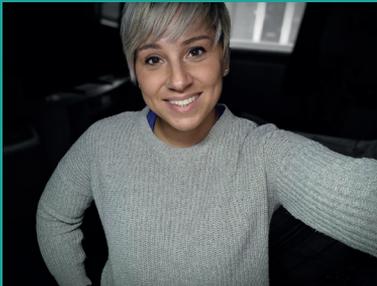
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I find that a little of what you fancy does you good!
Gill, living with follicular lymphoma



“

I found that pasta or potatoes, or anything high in carbs, helped me.
Melinda, living with diffuse large B-cell lymphoma (DLBCL)



More general suggestions you might like to consider

- Make things that can be frozen in advance of treatment.
- Say 'yes' to offers of help from friends and family.
- Treat yourself – my favourite is a packet of jelly babies.
- Try blowing your nose when you have a bad taste in your mouth.
- Be aware that something you really love before treatment might taste differently or you may 'go off' it forever because of associations with treatment.

Our website has more details about what makes a healthy diet, eating well during treatment for lymphoma and frequently asked questions about diet and lymphoma. See more at lymphoma-action.org.uk/Diet

This information comes from our Facebook user 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 you can email the magazine Editor at publications@lymphoma-action.org.uk or join our Closed Facebook Support Group at facebook.com/groups/LymphomaActionSupportUK

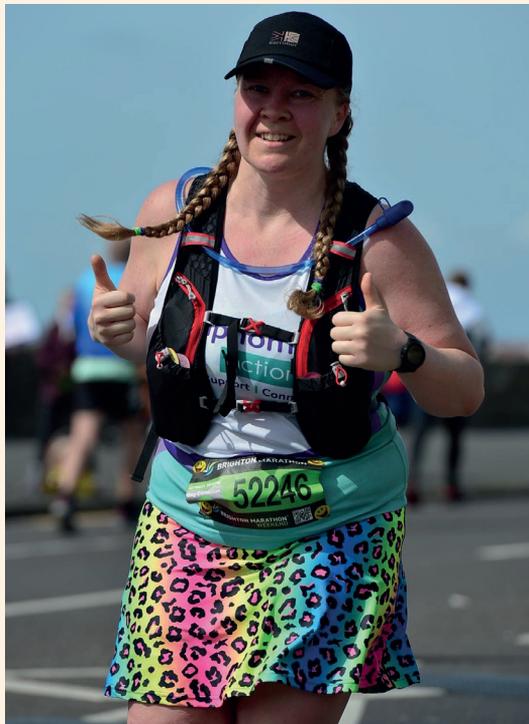
Virtual London Marathon

Do it your way on Sunday 2 October

Here is your opportunity to be part of the world's biggest marathon and earn the coveted finisher's medal.

On Sunday 2 October 2022 become part of the virtual London Marathon, completing 26.2 miles in 24 hours. This is a lovely alternative to the London Marathon; you cover the same distance, wear the same T-shirt and receive the same medal. However you can walk, jog or run on your own or get some friends to take part and run, walk or jog the 26.2 miles with you. You can run around your local area and you can even stop off for a cup of tea half way through if you fancy! Registration is free in July. Join #TeamLymphoma and secure your place today!

For more information, contact us at fundraising@lymphoma-action.org.uk or call 01296 619400.



'I really enjoyed my first Marathon, and even better raising money for Lymphoma Action'

Stacey (pictured above).

Mark (pictured left) ran this event for us last year:

'I completed the 2021 Virtual London Marathon in a modest time with many helpful supporters and a number of friends who completed the whole distance with me!

The time was not important, but the camaraderie, the support and the joy of taking part were absolutely priceless, and the memory of the experience will live with me forever!'

Keep on running...

Lace up your trainers for Lymphoma Action

Join us at the Richmond Running Festival (RUNFEST) – 10&11 September

RUNFEST is a weekend family festival that consists of six different distanced events, 10,000 runners, a music stage and a fitness expo.

A sea of purple Lymphoma Action T-shirts could really get people talking about lymphoma.

Contact us for more information at fundraising@lymphoma-action.org.uk or visit our website at lymphoma-action.org.uk/run

Bournemouth Running Festival – 8&9 October

This amazing running festival takes place on the weekend of 8-9 October and is a great family event.

Get your family and friends involved at this picturesque coastline event. If you have little ones, there's a kids' kilometer for 3-6 year olds.

For further information, please contact fundraising@lymphoma-action.org.uk, call the team on **01296 619400**, or visit lymphoma-action.org.uk/run

There's still time to join our Kenya trek, Spring 2023

Join us and our Maasai guides on the most incredible Kenyan adventure in the Great Rift Valley. We'll trek for over 90km across the jagged hills, grassy plains, and awe-inspiring wilderness of the Great Rift Valley. This is a blood cancer exclusive, bespoke trek with very limited places. Join a handful of other amazing supporters from #TeamLymphoma for this once-in-a-lifetime challenge!

Contact fundraising@lymphoma-action.org.uk for your fundraising pack.



A struggle for me and my boys

Jean talks about her diagnosis of Burkitt lymphoma, the challenges of treatment and the impact on her two sons.

I had been struggling with back pain, so my doctor referred me to physiotherapy. I adopted the strategies that physio were suggesting but it didn't improve things. The trouble was, once I had been referred to another service, I felt I needed to give it some time. But the pain was getting worse. It got so bad I couldn't find a comfortable way to lie down. In the end my cousin was so alarmed about the pain I was in that he took me to an NHS clinic in a hospital 25 miles away. They told me they were going to keep me in to do some investigations on my back.

I explained that it wasn't possible for me to stay in hospital as I have two sons who are 29 and 26 who both have cerebral palsy and other needs. I explained that I was their main carer.

I was very grateful that my cousin, my best pal Elaine and her husband were able to look after them for the first week. When I was transferred to a hospital in Glasgow, my sons went into a respite home.

I was to have an emergency MRI scan on Sunday, but it did not happen until Tuesday. I needed pain relief just to be able to lie on my back and stay still. This was quickly followed by a CT scan which revealed a mass on the bottom of my back attached to my spine.

I was told they would need to take a biopsy using a CT scan. I worried it would be painful, but the doctor numbed the area and I didn't feel a thing. The nurse came out and asked if I wanted to see the biopsy. It wasn't something I would have asked to see, but now it was offered, how could I say 'No'? It was so small. There were two tiny threads in a snake-like shape; one was white and one was red and clear. It amazed me that they could cut out something so small, and also that these tiny things were causing me so much pain.

A week later the consultant gave me the results of the biopsy and scans. I was told I had Burkitt lymphoma, a non-Hodgkin lymphoma. He explained it was a rare form of lymphoma and that although it was aggressive, it was also treatable.

The consultant said that I would need to be transferred to a specialist hospital 20 miles from home and that my treatment would involve staying in hospital for 4-5 months.

It was simply impossible. I had my two boys to think about. We had never been apart. And whilst I had friends, particularly my friend Elaine who helped so much, it wasn't possible for them to look after my sons for the amount of time the doctor was talking about. I simply couldn't allow my boys to be taken into care. I felt like I was being served a prison sentence.

Social Services arranged for my sons to go into a care home. I was so worried that they would be unhappy, but the social worker reported that they were doing really well. Both boys thought it was a holiday for them.

I was transferred to a specialist hospital for my treatment and for 4 or 5 months I was on so many drugs, I really didn't know what planet I was on. I was faintly aware that my boys were having fun; that was all I needed to know.

My treatment was CODOX-M/R-IVAC (rituximab plus cyclophosphamide, vincristine (Oncovin), doxorubicin and methotrexate alternating with rituximab plus ifosfamide, etoposide (VP-16) and cytarabine (Ara-C)) which is a very intense regime. I needed several tests to check that my heart, general health and fitness would mean I would be able to cope with the treatment. At the time I was a pretty fit 55-year-old, so fortunately

was suitable to receive this treatment. The nurse explained I would get worse before I got better. For the first couple of weeks I was so tired I could barely keep my eyes open. The first part of my treatment was CODOX, but for the last 3 days I was given methotrexate to prevent the lymphoma spreading to my central nervous system. This was particularly difficult.

My hair started to drop out about ten days into chemotherapy and the nurse came and shaved it off for me. I didn't expect to lose it so soon, and found I avoided looking at myself in the mirror as it didn't look like me and I didn't feel like me.

After 13 days I had a week off treatment for my body to heal. However I became neutropenic, meaning my immune system was weakened as I had low neutrophils – a type of white blood cell that helps the body fight infection. With COVID around, this was a worrying time. Everyone who was near me needed to be gowned up and keep as far away as possible.

I just wanted a hug, but that wasn't possible, and it felt like for the first five weeks I was crying all the time. I wanted to go home and I wanted to be with my boys.

After the first week, I felt so exhausted that I said I couldn't do it any more. They asked me if I was specifically refusing treatment and made it clear that if I did not continue with the treatment I was going to die. They were very clear about what would happen and that I would be transferred into ITU for palliative care. The doctor was right in what he was saying. My carer came in and told me that she was so pleased that I had made the decision to continue with treatment.

Looking back now, I'm so glad my carer had this conversation with me – I was on so many drugs and morphine for the pain that my mind was playing tricks on me.

The IVAC element of the treatment was a breeze compared with the CODOX, although it was at that point I struggled with mouth ulcers. I was given several mouthwashes that helped, but I was still struggling with them. I ate ice-cream and yoghurt, just letting it melt in my mouth. Really cold milk helped too. I also needed to have my medication in liquid form so that I could get it down my throat, as swallowing tablets was so hard.

I dreaded the next cycle of CODOX, but found the second time it was much more manageable. Whilst the first time round I could barely do anything for myself, this time I was gradually able to do more and move around the hospital. I was connected to a chemotherapy trolley and although it wasn't a friend I would have chosen, I fondly named it Metal Mickey. I couldn't lose him; where I went, he went!

I had a scan half way through treatment and they said that things were going well, and that hopefully the next two interventions would clear it completely, which it did.

I didn't know what the word 'remission' meant, but when it was explained to me, it was overwhelming. I reflected back on the day I said I did not want to carry on with treatment and am so glad they didn't just take me at my word.

The tumour on my spine has left me with pain, but luckily it is manageable. It is a constant reminder of what I have been through.

I am told it may still improve because it is only 7 months since treatment finished, and there can be improvement for at least two years post-treatment. I realise I might be on pain killers for the rest of my life, and at the moment I am using elbow crutches to help me walk, but I feel very fortunate. I feel I have had a second chance of life.



Jean's sons Gary and Andrew

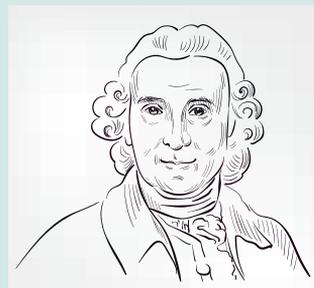
My boys are getting used to seeing their mum with elbow crutches. I talked with my friend about how much I should tell them, but we felt they would struggle to understand the complexity of what I had been through, so we settled for having a sore back. Which is true anyway.

I did feel lost for a while and had counselling through Macmillan, which I found really helpful. I also started a photo album of my lymphoma journey, which was really therapeutic for me. Lymphoma Action have also been enormously helpful and joining the Closed Lymphoma Action Facebook Group allowed me to feel part of a community, which has made me feel far less isolated. I also found it really interesting to read other people's lymphoma stories, but think the website needs more about Burkitt lymphoma!

Clinical Trials - how it all began

The first clinical trial took place 275 years ago, on 20 May 1747. Here we describe the reason for the clinical trial, and the impact it has had on science and medicine ever since.

Scottish naval surgeon's mate James Lind was aboard HMS Salisbury. Scurvy was rife amongst the sailors, but there were conflicting ideas about how best to treat it. James Lind decided to confront this uncertainty by treating his patients within a clinical trial comparing the proposed remedies.



He took 12 men experiencing similar symptoms of scurvy, divided them into six pairs and treated each pair for six days with one of the following: cider, elixir of vitriol (diluted sulphuric acid), sea water, spices, vinegar, or two oranges and a lemon.

There was a noticeable improvement in the pair eating the fruit, providing Lind with the evidence required for the link between citrus fruits and scurvy. Lind conducted what is thought of as the first clinical trial and he laid the foundations for modern clinical research.

Although we don't run clinical trials at Lymphoma Action, we have a database of clinical trials called Lymphoma TrialsLink, which is a listing of trials open in the UK for people affected by lymphoma. If you would like to take part in a clinical trial, you can take the trial summary from our database to your specialist for a discussion.



Talking about peripheral neuropathy and itch



Lymphoma has a breadth of complex symptoms that go with it, which are often vague. In addition treatments can have side effects which can last beyond the length of the treatment.

Here we share some insight into peripheral neuropathy and itch as discussed by Dr Dan Monnery at a recent webinar (see page 27 to find out how to access the webinar).

Treatment for lymphoma destroys lymphoma cells, but can also damage healthy cells, causing unwanted 'side effects'. These are usually temporary. Different factors affect which side effects a person may experience, including the types of treatment, how much and how often you receive it. It is important to talk to your medical team about any symptoms or side effects you experience so that they can offer support and advice to help you to manage them.

Peripheral neuropathy

Peripheral neuropathy means there is temporary or permanent damage to the nerves of the peripheral nervous system. The nervous system works a bit like a network of electrical wires. Specialised cells (receptors) and nerves within it pick up and carry signals and messages between different parts of the body. However, if you have peripheral neuropathy, this communication is disrupted.

For people with lymphoma, peripheral neuropathy might be caused by lymphoma infiltrating the nerves and damaging them. Alternatively, as the body is responding to the lymphoma and trying to fight it off, the nerves can get caught in the crossfire and be damaged. It can also be a side effect of some treatments for lymphoma.

Peripheral neuropathy can cause a burning sensation or a loss of sensation. It is usually noticed in the hands and feet when people find that they struggle to write, do up buttons or have a loss of balance.

Although hands and feet are often the focus, the peripheral nerves are responsible for much more than that:

- They assist your blood pressure when you go from a seated position to standing, so if your peripheral nerves aren't working, your blood pressure can drop when you stand up, and sometimes it can result in a fall.
- They make your bowel and bladder work, so peripheral neuropathy can result in constipation or an overactive bladder.
- They keep your muscles loose when you are at rest, so if they are damaged you can struggle with cramp.
- They tell your body when your stomach is full and needs to empty into the bowel. If this is not working you will feel full all the time and may struggle to eat.

Managing peripheral neuropathy

The problem with peripheral neuropathy is that nerves don't heal very quickly so people can be left with this after-effect even if treatment has been fully successful.

Peripheral neuropathy can affect people's independence and mobility, and can also cause pain.

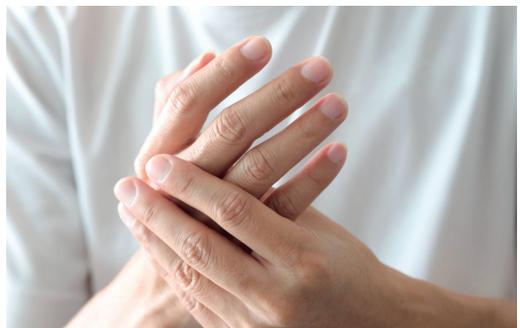
It is important to reduce the impact it has on people's lives by dealing with the symptoms. Here are some approaches your medical team may use if you are struggling with peripheral neuropathy:

- For pain, several medications may be effective, such as duloxetine, gabapentinoids and tricyclic antidepressants.
- If it is affecting your function, physiotherapy and occupational therapy may be needed; the earlier the better to reduce the impact on independence and lifestyle.
- Fludrocortisone can help if people have blood pressure problems when standing up from the sitting position.
- For muscle cramps, pridinol or baclofen may be used.
- For an overactive bladder, oxybutynin may be helpful.

What people report as being helpful to manage peripheral neuropathy

Although there is no research or evidence to support these approaches, and they will only mask the symptoms, this is what people have reported as being helpful:

- exercise, such as swimming and walking
- acupuncture and reflexology
- if the PN is causing a burning sensation cooling with a cream like aquacool 2% may help
- if your hands and feet feel cold as ice, then chilli extract creams such as capsaicin 0.025% can be helpful.



Itch and itching

Itching can be a symptom or a side effect of lymphoma. Scientists don't yet fully understand what causes itching as a symptom of lymphoma. However, it is thought that it could be due to cytokines – chemicals released in your immune system as it fights lymphoma cells. It is thought that cytokines irritate the nerves in your skin and cause itching. For many people, the itching starts to go away once treatment for lymphoma starts. However, it can continue during, or even after, treatment.

For a long time it was thought that itching was related to histamine (a chemical found in some of the body's cells). If you get bitten by an insect or are sensitive to a medication or substance, your body responds by releasing histamine, which causes many symptoms of allergies including itch. For that, people take an antihistamine which works very well.

Lymphoma is different in that it has a number of things going on that can be triggering the itching sensation, such as:

- **Histamine** – a chemical found in some of the body's cells that cause symptoms of allergy, such as sneezing and itching.
- **Interleukins** – which are a type of cytokine (a chemical released by your immune system as it fights off lymphoma cells).
- **Substance P** - which is a pain-related neurotransmitter but also responsible for turning on the itch sensation.
- **Allergic reaction** - where your immune system is activated and releases substances called proteases. Proteases have their own receptors in your skin which can stimulate itch.

Itching can be extremely debilitating and there are people with lymphoma who are really troubled by it.



This means that when your medical team come to treating itch, they have to think about what is causing it. In many cases a couple of methods will need to be tried before the root cause is identified. This can be frustrating for people as it can look as though your doctor is simply guessing. In reality there are a number of mechanisms involved in itch and it is about making an informed guess on which one to begin with.

Persistently scratching the itch can break the skin and introduce infections. In addition, continuous itching can have an impact on mood and day-to-day life. It can cause sleep disturbance, resulting in lack of energy and low mood, which can in turn make going to work and socialising difficult.

Managing itch

There are things you can do to support good skin health generally, which may help:

- Keep your skin well hydrated by drinking plenty (the NHS suggest 6 to 8 cups or glasses of fluid a day, such as water, lower-fat milk, sugar free drinks, tea and coffee).
- Use emollient creams: moisturising treatments you apply to your skin to soothe and hydrate it.
- Use non-perfumed soaps.
- Use non-synthetic fabrics (avoiding materials such as nylon, polyester and acrylic).

Itch can be a symptom of lymphoma, so treating the lymphoma may deal with some of the problems.

If the itch is being caused by **histamine**, there are a number of antihistamine treatments that can help, such as Piriton. Although there is a trend towards non-drowsy antihistamine treatments, if you are struggling to sleep, then the option that makes you drowsy may be helpful.

If the itch is **interleukin** driven from the lymphoma itself, then chemotherapy treating the lymphoma may help. If it is due to inflammation and allergic responses to lymphoma, chemotherapy might help again, but steroids may also be useful. Your treating team will be cautious about using steroids as they can reduce the ability to get an accurate biopsy result and might interfere with other steroids if they are forming part of your lymphoma treatment.

If the problem is **substance P**, then capsaicin (a cream made from chilli extract) could help. Capsaicin is an active component of chilli peppers, which belong to the genus *Capsicum*. Chilli causes a burning sensation and depletes the nerve cells of substance P, so although it will burn for a bit, it gets rid of substance P which could be causing the itch. You want to have your skin intact (not broken from itching) to use this, otherwise it could be very painful.

More generally, menthol cream which contains dermacool 2% cream has been found to be helpful. It produces a cold sensation, which can be helpful in the management of itch.

This is an extract from a webinar held in May 2022 in which Dr Dan Monnery, Consultant in Palliative Medicine at the Clatterbridge Centre was joined by Charlotte Bloodworth, Advanced Nurse Practitioner in Wales and Nikie Catchpool at the Bath Centre for Fatigue services to talk about some of the common symptoms and side effects of lymphoma. You can watch the webinar at lymphoma-action.org.uk/PhysicalWellbeing



I appreciate my life much more now

Lyle talks about his diagnosis and treatment for Hodgkin lymphoma

I was getting ready to take my girlfriend out, and noticed in the mirror that my neck looked bigger on one side. I could feel a big hard lump on the side of my neck.

I called my GP who suggested I go in so that she could take a look. There was absolutely no messing around, and I was referred to ENT (ear, nose and throat) at my local hospital for a biopsy. Two weeks later I was diagnosed with Hodgkin lymphoma.

If you spot anything you are concerned about, or you don't feel right health-wise, get it checked out.

Looking back, I never noticed any of the typical symptoms, such as losing weight or having night sweats. Without the lump I wonder whether I would have noticed?

I knew nothing at all about lymphoma, and was given the Lymphoma Action book, *Young person's guide to lymphoma*, which was a massively useful resource. The specialist nurse warned me about searching online too much, so I didn't look widely, especially as I found I had everything I needed from Lymphoma Action.

As I had just turned 19, I was asked if I would prefer to be treated in my local hospital or for my care to be transferred to a Principal Treatment Centre where they have specialist facilities for treating young people. A friend of mine was being treated for sarcoma in a Principal Treatment Centre, so I decided to choose that option. I have to say the hospital and the team were absolutely brilliant.

I was to be treated with four cycles of chemotherapy. My first two cycles were with a combination called OEPA (Oncovin, Etoposide, Prednisone and Adriamycin) where I had two weeks of treatment followed by two weeks off.

After the first two cycles I had a mid-point scan, which looked as though the cancer had gone, so my treatment was changed to COPDAC (cyclophosphamide, Oncovin, prednisone and dacarbazine) which is less toxic and in fact during this second phase of treatment my hair started to grow back.

I managed pretty well with the treatment. I was neutropenic after my first two cycles of chemotherapy, and experiencing some pains, but otherwise I didn't really struggle too much.

Before my diagnosis, I was working as an apprentice in financial services. Being a 'numbers person' I really enjoyed the role, working four days in the office, and studying for the other day. The study element of the apprenticeship needed to be completed within a two-year limit, otherwise that part was classed as a fail. However, the organisation was incredibly supportive, giving me six months off during my treatment and ensuring the timescales were expanded so that I could complete my studies. I'm due to finish my apprenticeship this September.

Now that restrictions have eased I am back working in the office environment. I have had COVID-19 but am pleased to say it didn't really affect me very much; I have had all my jabs. In fact, my mum and brother seemed to struggle more with COVID-19 than I did.

Having Hodgkin lymphoma has massively changed my perspective on life. In the past I never thought about health or the importance of the help charities can make to people's lives. I'd been fortunate that I hadn't needed support before. But I realise that in most cases people need support through no fault of their own. That is why I feel so passionately about supporting Lymphoma Action.

I decided to set up a Just Giving page and circulated it to friends. I had hoped to raise around £1,000 but was amazed to raise over £8,500. My mum, who had run the London Marathon in 2011, is running it again this year, but this time supporting Lymphoma Action, so that they can continue to help people like me and my family.

I look at things in a totally different way now and am incredibly grateful for what I have. I appreciate my family, friends and girlfriend so much more. I've also been struck by just how kind and caring people who you don't even know can be. People involved in my care, people donating money in my name, people you meet while undergoing treatment. It's pretty humbling.

I am also taking more care of my body now. In fact, I feel healthier than I did before my treatment. I have joined a gym and am doing exercise 5 or 6 times a week now. This isn't something I did before, but I'm really enjoying it.



Lyle and his girlfriend Liv



Going out and taking a break

Restrictions may have eased, but we know many people are still worried about COVID-19 and some are continuing to shield. This isn't surprising as we know that COVID-19 is still very much around. However, you might worry about the impact of your decisions about seeing people on your relationships, particularly if their feelings and approaches differ from yours. The important thing is to go at your own pace, do what feels OK for you and don't be afraid to say 'no' to things that make you feel uncomfortable.

Meeting up and going out

Here are some ways to meet up with others whilst reducing your risk of catching COVID.

- Take it step by step, and only do what you feel comfortable doing. Try not to avoid things entirely, but start with activities that are important to you and feel achievable, like meeting a close friend or a family member for a coffee outside, and gradually build up from there.

- Talk with family and friends about how you feel. This can minimise the risk of people feeling hurt or offended.
- Consider meeting other people outdoors to keep your risk as low as possible.
- Open windows and doors when meeting inside to let plenty of fresh air in.
- If you are eating out at a pub or restaurant, think about where you feel comfortable sitting. The risk is lowest outdoors. If you choose to sit indoors, try to find a quieter, well ventilated space if possible.
- If you are planning a trip out, think about where you feel safe going. You could consider outdoor attractions, or larger, well ventilated venues where it's easier to keep a safe distance from other people.
- When you're out in public, try to stay a safe distance away from other people. You might find our 'Distance Aware' badge a helpful way to remind others to give you space if they can. If you are going to the shops, or visiting other public places, it is safer to go at a quiet time of day if you can. Remember you can still shop online if you prefer.

- Avoid public transport if you can. If you can't avoid it, try to travel at quieter times of day.
- Although face masks are no longer a legal requirement in most settings, you can wear one if it makes you feel more comfortable. You could also ask others if they'd consider wearing a mask or do a COVID-19 test before meeting up to help protect you. Being aware of everybody's fears and expectations can help to avoid conflict.
- If you're invited to an event or situation that you don't feel comfortable attending, you could suggest an alternative that you do feel comfortable with.
- If you have lymphoma and you plan to travel to another country, it is important to arrange suitable travel insurance before you go. Our website has more information about choosing travel insurance at lymphoma-action.org.uk/Travel-insurance or you can call our helpline on freephone **0808 808 5555** to talk it through. Lines are open 10am to 3pm, Monday to Friday.
- Not every country has access to antibody and antiviral treatments for COVID-19. Your doctor **cannot** prescribe you antibody and antiviral treatments for COVID-19 to take with you in case you test positive while abroad. If you do catch COVID-19 while you are abroad you may not be able to access these treatments like you would in the UK.

...and if you're thinking of foreign travel

After months of change and restrictions you might be thinking of a holiday. Here are some things to consider while planning your holiday.

- Every country has different COVID-19 restrictions. You can check foreign travel advice for all countries you will visit or travel through on GOV.UK. This will tell you if the country will allow people to enter from the UK, whether you will need to show proof of vaccination status or proof of a negative COVID-19 test and if you will need to quarantine on arrival. Foreign travel advice will also tell you if the UK government advises against all but essential travel to the country.
- You could wear a mask on public transport and in crowded places. Medical masks and respirator masks can provide you with better protection from COVID-19 than cloth masks.
- Some treatments for lymphoma like chemotherapy and radiation can make the skin more sensitive to the radiation from the sun. To protect your skin, apply a sunscreen with a sun protection factor (SPF) of at least 30 that protects against both UVA and UVB rays. Avoid spending time in direct sunlight between 11am and 3pm and wear a hat to protect your head and shoulders.



Recognising our marvellous volunteers



On 6 June we held our first ever Volunteer Recognition Awards! The event recognised the huge breadth of skills, expertise, time, support and commitment of all our volunteers.

Lymphoma Action's Director of Services, Dallas Pounds, presented 128 awards for length of service, as well as an incredible 32 for outstanding contributions.

Dallas Pounds, said 'we owe so much to all of our amazing volunteers for the time, energy and compassion they offer to those affected by lymphoma. It was such a pleasure to get to thank so many of them individually and applaud the huge difference that all of our volunteers make.'

'We were very excited to launch this recognition event to celebrate our volunteers, who have such a positive impact and enable us to inform, support, and connect with thousands of people affected by lymphoma.'

Carly,
Volunteering Development Manager

'We are looking forward to having the opportunity to celebrate our volunteers and their invaluable efforts every year moving forwards.' says Carly Benton, Volunteering Development Manager.

Listen to our latest podcast where two of our volunteers, Mark and Penny, talk about their volunteering experience at lymphoma-action.org.uk/VolunteerPodcast

If you'd like to be part of our volunteer community, get in touch at lymphoma-action.org.uk/Volunteering or email volunteering@lymphoma-action.org.uk

A couple of highlights from the event

Marguerite Russell (*pictured right*) received a special mention as she is our longest serving volunteer, having supported us for an amazing 27 years.

Our Norfolk Fundraising Group were recognised for their exceptional dedication. Over the past 20 years they've raised amazing amounts of money and awareness through the dedication and support of the wonderful team of volunteers.



Many of the volunteers told us how much volunteering makes them feel part of a community and how they enjoy the role they do, like Judit (*pictured left*) who said: 'The award was completely unexpected, I was very humbled with tears in my eyes. I was and still am delighted to have been nominated for and having received this award. What I do with Lymphoma Action comes naturally to me, I truly enjoy volunteering.'



So much of what we do is made possible by our fantastic volunteers. Here's a summary of some of the ways they support us – and people affected by lymphoma.

- Over 80 volunteer **Buddies** with lived experience of lymphoma have supported others going through a similar experience.
- In 2020, in response to the pandemic, our Support Group Meetings moved online. Since then 27 volunteer **Online Support Facilitators** have supported 534 meetings.
- In 2020 we developed '**check-in and chat**', to keep in touch with people over the phone.
- Our Closed Facebook Group goes from strength to strength, thanks to our team of 8 **Volunteer Moderators**.
- Live your Life workshops equip people to live with and beyond lymphoma, thanks to our 12 **Facilitators**.
- Our 48 **Reader Panel** volunteers ensure our information is easy to understand, clear and answers all the questions people may have on a topic.
- Our **Medical Advisory Panel** of 36 health professionals, provide medical expertise.
- Our 22 **Community Volunteers** support events throughout the UK on our behalf.
- Our 6 **Development Board Members** provide insight and support to our Fundraising Team.
- Through the 41 volunteers on our **Insights Panel**, we have gained a wider perspective on new ideas and projects.
- Our 10 members of our **Volunteer Forum** help us to drive volunteering developments.
- Volunteers share their specific skills across a range of **bespoke roles** from administration, consultancy, creative design, photography and project support.

Making your donation go further with gift aid

At Lymphoma Action we value every penny given to us by our donors, and see the huge difference these donations make to people affected by lymphoma. But did you know you can make those donations go even further – at no extra cost to yourself – through Gift Aid?

giftaid it

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 sign up to Gift Aid, the government will add an extra 25p to every £1 you give Lymphoma Action.

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

You can add 25% today by completing a Gift Aid form at lymphoma-action.org.uk/gift-aid If you'd like to gift aid donations you have already made, then please call us on **01296 619419** or email fundraising@lymphoma-action.org.uk

Last year supporters like you helped us raise an additional £100,000 with Gift Aid. **Thank you.**

Cause to Celebrate

We're so grateful to all the people who chose to ask for donations instead of receiving presents for their birthday, wedding and anniversary celebrations. Since the beginning of last year, our lovely celebration supporters have collectively raised over £53,000 for us. It's such a wonderful way to show those affected by lymphoma how much we all care.

If you have a big birthday, wedding, anniversary or other celebration coming up and would like to donate to Lymphoma Action, please do let us know. Our team will be on hand to help you set up a celebration fundraising page (we recommend using Facebook or JustGiving). And if you wanted to give your donors a small gift in return for theirs, you can order our little books of wildflower seeds online at lymphoma-action.org.uk/Shop



This fabulous cake was made by a supporter.

Did you know our helpline offers Language Line?

Our helpline offers the opportunity to talk to us in a language other than English. This helps us to ensure that we can be there for anyone who would like to speak to us.

What is Language Line?

Language Line is an interpreting service. It means that we can have a three-way helpline call with you, and you can speak to us in one of over 240 languages. It's free to use and Language Line doesn't record your call, so it is still confidential. Their interpreters are also experienced in communicating complex health issues.

How do I use Language Line?

You will need to call us to ask for this service. If you can't make the call yourself, you can ask someone to do this on your behalf.

Call the helpline on freephone **0808 808 5555** between 10am and 3pm, Monday to Friday, and let us know that you would like to speak to us in another language. We'll need to know your first name, phone number and the language you'd like to use. We then pass these details on to Language Line, and they will call you back. Once connected, we can then talk to you through this interpreting service. What you say will be relayed to us, and our reply will be relayed back to you. You can just talk as if you are talking directly to us. At the end of the call, you just hang up the phone as usual.

If you'd like to know more, visit our website at lymphoma-action.org.uk/language-line

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

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.

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

Closed Facebook Support Group – join this popular group at 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

Videos – we have videos on various topics around lymphoma, including information about COVID-19, and wellbeing. Find out more at lymphoma-action.org.uk

Lymphoma Voices – our podcast series includes personal experiences and medical opinion. Find out more at 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

Announcing!

Whether you whack on a wig (purple is a good colour!), big up your beard, lop your locks or go the whole hog and do a head shave, our Big Hair Dare is a great way to fundraise and support people affected by lymphoma.

Go solo or ask your school, college, university or workplace to get involved.

the big HAIR dare



Grab a fundraising pack lymphoma-action.org.uk/bighairdare
email the fundraising team fundraising@lymphoma-action.org.uk
or give us a call on 01296 619400.