

lymphoma matters

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

- Visit lymphoma-action.org.uk/Donate
- Call us on 01296 619419

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As per our policy, they have no influence over our content.



Ropinder Gill
Chief Executive

Latest information on the COVID-19 autumn booster and the flu vaccine on page 10.



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

Feeling animated

Welcome to your latest edition of *Lymphoma Matters*. Because of the generosity of our supporters, we are able to send this magazine free of charge to around 15,000 people, many of whom now get this magazine in its online format. We get incredible support from our community and would like to thank everyone including our amazing London Marathon runners who we cheered on earlier this month and who have already raised a wonderful £159,000.

This magazine is a tangible resource for people. However, we also use your donations to influence policy which feels less tangible, but which is crucially important in effecting change for people affected by lymphoma. For example, we want Evusheld, a preventative COVID treatment, to become available on the NHS and so we are responding to the health technology assessment (HTA) which paves the way for this to happen. This year we have already been involved in 10 HTAs relating to treatments for 5 different lymphoma types. You can read more about our policy work on page 31.

Last year we undertook a research project to help us understand how we can improve our services to help reduce health inequalities. Following this we have put in place several initiatives to help make it easier to access support from us, including the launch of two new animations: *About Lymphoma Action* clearly explains all our services and *What is lymphoma?* gives a simple and accurate overview of lymphoma. We hope you find these animations helpful and a useful resource to signpost friends and family to.

And it's not just information that we're looking to improve or expand. In 2023 we are introducing a wider range of online support meetings, including meetings for specific types of lymphoma and stages of treatment. You can find out more about what we hope to achieve in our revised strategy 2023–2025: lymphoma-action.org.uk/AboutUs

Wishing you all the very best for the remainder of 2022.

Ropinder Gill
Chief Executive

Lymphoma Action gains PIF TICK accreditation



Patient Information Forum

We are delighted to have been awarded the PIF TICK – the UK’s only assessed quality mark for print and online health and care information.

To become a ‘trusted information creator’, we had to undergo an assessment showing we met 10 key criteria when producing our patient information. We received the accreditation in July and will be proud to add the PIF TICK logo onto the information we produce in line with these guidelines.

You can find out more about this quality mark at piftick.org.uk

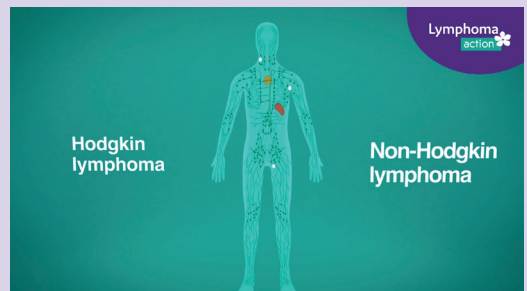
Two new animations launched

We have just launched two new animations which we hope will be helpful resources for people affected by lymphoma.

What is lymphoma?

Lymphoma is a complex condition, and we often hear that people have never heard of it before they receive a diagnosis. We have therefore produced a short animation that explains what lymphoma is and the treatments available. We hope this will be a valuable explainer for people and a useful resource to signpost people to when explaining what lymphoma is.

Check out *What is lymphoma?* at lymphoma-action.org.uk/WhatIsLymphoma



About Lymphoma Action

For over 35 years we’ve been introducing more and more ways of informing, supporting and connecting people. Our website, books, videos, webinars, conferences and podcasts provide people with information about lymphoma. Our Online Support Groups, Closed Facebook Group and Buddy Service connect people and we offer support through our Helpline and our Live your Life programme. Watch our new animation which brings this all to life and explains all the ways we can help you and your family.

Watch *About Lymphoma Action* at lymphoma-action.org.uk/AboutUs

Lymphoma Action welcomes two new Trustees

Harriet Outred (right) and Susan Daniels (below) joined our Board of Trustees in July. Harriet is a qualified solicitor working in risk and compliance and Susan has worked in healthcare for more than 20 years. As well as bringing invaluable expertise, both Harriet and Susan have personal experience of lymphoma.

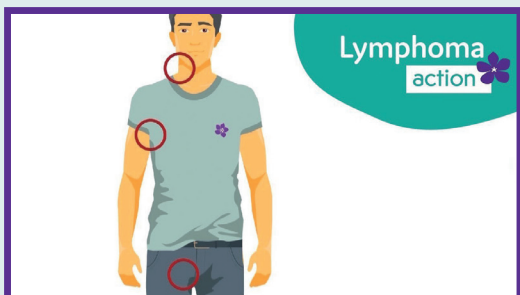


Harriet is living with a rare T-cell skin lymphoma, which brought her into contact with Lymphoma Action, where she volunteers as a member of the Reader Panel. Harriet comments: 'I hope to draw on my professional and personal experience of living with lymphoma to help the Charity achieve its objectives.'



Susan was diagnosed with Hodgkin lymphoma in 2013 and her father was diagnosed with non-Hodgkin lymphoma a year later. Susan is committed to supporting other families and working towards better outcomes for those affected by lymphoma. As Susan says: 'My family and I have been living with lymphoma for the best part of a decade and I have regularly looked to the lymphoma community for support over the years. I am delighted to be able to help Lymphoma Action in supporting families like mine.'

Film on symptoms reaches 1 million views



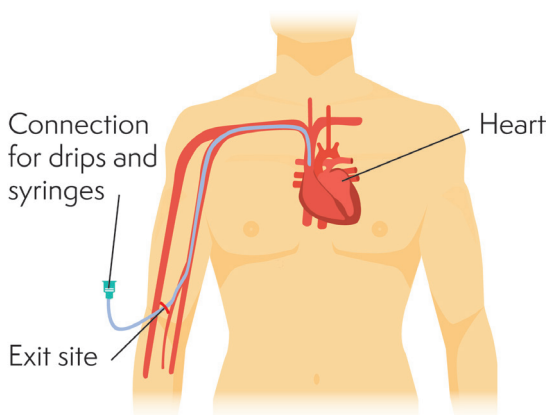
Our medical film, featuring Dr Andrew Davies explaining symptoms of lymphoma, recently reached 1 million views.

You can watch the film at lymphoma-action.org.uk/SymptomsFilm where Dr Davies outlines the key symptoms and explains why lymphoma can be so hard to diagnose.

Maintaining your PICC line

Many people undergoing treatment for lymphoma will have a PICC line fitted. PICC lines might be used if you are having ABVD chemotherapy for Hodgkin lymphoma, salvage treatment or having a transplant.

The PICC (peripherally inserted central catheter) line stays in place for weeks or months and is a safe and convenient way to have chemotherapy for lymphoma. A PICC line is a soft tube that goes in through a vein in your arm above the bend of your elbow and is inserted by a trained nurse using an ultrasound scan. Once fitted, your line is covered with a simple dressing to protect it and to keep it in place.



Placement of a PICC line

The two main concerns about PICC lines are that they can sometimes become infected and occasionally a blood clot can develop around them.

It is important to contact your hospital immediately if you develop any symptoms, however mild, as these can be extremely serious. Symptoms to look out for include:

- A high temperature (above 38°C)
- Swelling or pain in the arm
- Redness or heat around the site of the line.

To avoid problems with your PICC line:

- Get the dressing on your PICC line changed every week.
- Have your PICC line flushed regularly. Don't be tempted to put it off as that can increase your risk of infection and cause the line to block.
- Keep your arm active to avoid the risk of clots.
- Don't let the tips of your line rest in water. Use a special cuff (available on prescription) to cover the line if taking a shower or bath.
- Recognise how much of the line is hanging out of your arm. If it gets longer, it may mean the line is no longer in the correct place. If this happens, it is important to contact your medical team.
- Keep your PICC line covered to avoid it becoming dislodged. Without covering, it could get pulled out, for example by a child.
- If your PICC line becomes displaced, tell your medical team immediately. They may be able to push it back, or it may need to be re-placed. A stabilisation device may need to be used to hold the line in place.

**With thanks to Charlotte Bloodworth,
Advanced Nurse Practitioner in Haematology,
University Hospital of Wales, Cardiff.**



Being as fit as possible helped me to recover

Martin talks about his diagnosis of diffuse large B-cell lymphoma and his treatment with chemotherapy and radiotherapy

In 2017, I was 64 and I had taken early retirement. At the time I was working as a Professor at the University of Salford, although I had been a cancer charge nurse before moving into research and teaching.

That November I noticed that one of my tonsils was enlarged. It was causing me difficulty swallowing so I made an appointment to see my GP.

My nursing background told me that something was wrong, but the nurse I saw didn't think there was anything for me to worry about. She suggested I go away and come back in two weeks time if things hadn't improved.

I went back two weeks later and had taken a photo on my phone, which showed the lump very clearly. I was referred to an ENT (ear, nose and throat) specialist.

I should have pushed to be seen under the 'two week wait' rule (for suspected cancer), but fortunately an appointment did come through a few weeks later.

I was seen in early February 2018 by an ENT surgeon. He explained that he was going to put a scope up my nose and into my throat. This procedure sounded uncomfortable and worried me, but he was excellent and I felt nothing. I was also given an MRI scan.

When I went back to see him he told me to sit down, which immediately sounded ominous. He explained that I appeared to have a tumour, which was likely to be cancer, but at that time they did not know what type. I was to have a tonsillectomy (removal of the tonsils) as a biopsy. I was a little uncomfortable for a couple of weeks after the surgery and struggled to eat. I lost a stone in weight and seemed to live on ice-cream and rice pudding.

My wife and I then returned to hear what the biopsy results revealed. I was told I was going to be referred to haematology and the biopsy suggested it was a type of lymphoma. They also said that it would be haematology who would get hold of me to explain what would happen next. To my surprise, soon after that meeting, I received a call on my mobile from a consultant. He explained that I had lymphoma but that they needed to find out what kind. He said I needed to have a PET scan and that he would try to get the results quickly, as they were keen to start treatment as soon as possible.

I had the choice of being treated in a local hospital or a major cancer hospital; this was something I thought about as I was waiting for the results of the PET scan. I decided to wait to see if treatment would be straightforward or more complicated, and so I chose to have my treatment locally.

I was diagnosed with diffuse large B-cell lymphoma and told I would follow the European protocol of R-CHOP chemotherapy (rituximab plus cyclophosphamide, doxorubicin or hydroxydaunorubicin, vincristine: Oncovin® and prednisolone). It was also explained that diffuse large B-cell lymphoma was a really treatable form of lymphoma.

When I had been nursing, I had spent time nursing people with leukaemia and lymphoma, and I recall the treatment being pretty grim. The main chemotherapy drugs (CHOP) have been around for over 40 years, so initially I didn't think things had changed so much. What has changed since my nursing days is the treatment and prevention of side effects from R-CHOP, which has been transformational. I had been terrified of sickness, but that was managed brilliantly and I experienced no nausea at all.

I took the approach of one day at a time and this worked well for me. I did have one episode of infection but the A&E department dealt with it swiftly once they knew I was in treatment.

What really strikes me is how much the treatment of side effects has improved.

The 'R' element in R-CHOP is rituximab, a monoclonal antibody. Its addition to the protocol has made an important difference to outcomes.

The nurse specialists and the rest of the team there were excellent. I knew from my experience as a nurse that health professional staff can be the worst patients, but they took my detailed questions in their stride.

After three rounds of R-CHOP my clinical team said they wouldn't do any more. They were confident that the chemotherapy and 15 sessions of local radiotherapy should clear anything up that may be remaining. Unsure about this I checked it out with my nephew, who happens to be a lymphoma specialist, and he was also sure that this should be enough.

There was one element of the R-CHOP chemotherapy, the vincristine, that I was concerned about because I did not know whether I was fit enough to have it. However, although I was over 65, my exercise test results looked good, so it was agreed that it should not cause me any difficulties. I did get tingling and numbness because of the vincristine, but that has gone now.

I think I already knew that being as fit as possible in the time I had was important even before diagnosis. I was already going to the gym as well as cycling.

I realise now how much this may have helped with my recovery. Where this is possible for people, being as fit as possible before treatment is really helpful. I think this is now becoming known as 'pre-habilitation' and is something people are more and more encouraged to do.

About a month after R-CHOP I was feeling much better and things had settled down, so I was quite nervous about starting radiotherapy.

The radiotherapy was going to be aimed at my tonsil area, so I needed to have a mask made to ensure it was targeted at the correct place and to keep my head still. It was the first time in my life I had a tattoo, so that they could mark where I needed the treatment. It was actually only a dot!

They fitted me for a mask and explained how long I would be in it, as many people find it claustrophobic. It was a really weird sensation being clamped to the table by a mask, but it was only for 3 or 4 minutes. In a way it was reassuring that it was safeguarding me, and it was over pretty quickly. I also knew I could yell and they could release me swiftly. I decided to do a bit of meditation to get me through it. While in the machine one day I noticed images of star shapes and the nurse explained that was for the children and babies. I then realised it was definitely 'do-able'.

Radiotherapy made my throat a little bit sore and by 2-3 weeks I could only manage to eat yoghurt or softer foods. I was given Dofflam, a green fluid which helped with my mouth issues and the whole thing was then more manageable.

Radiotherapy had a cumulative effect on me. I was having difficulty swallowing and everything felt swollen, but I knew I still had 3 or 4 more sessions. By the last session I was finding it quite difficult, but I knew it would be worth the effort.

I had an uncomfortable feeling in my throat for months and feared it was a recurrence of the tumour. I went back several times, but fortunately it was not returning. Both my CNS and consultant were happy to see me if I was worried about anything, which was enormously reassuring. What we realised was that the surgery and radiotherapy had changed my throat, and it took some time to settle. Once it had settled, it felt very different.

When treatment finished I felt like I was being cut loose. I had developed a nice relationship with the staff, and in some ways missed the regular contact. I happen to have another condition treated by my team (an unrelated genetic iron overload disorder) which means that although I would normally have been discharged, I am still seen every four months. Even so, the staff were very clear on what to look out for and told me not to hesitate if I have any concerns.



Martin with his wife Alison and dog Mollie.



Updates on vaccinations and boosters

Should I have the flu jab?

The flu vaccine is given free on the NHS to people with certain health conditions, which includes lymphoma. The list of people who qualify for the flu jab also includes people over 50, frontline health and social care workers.

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

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

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

Important advice:

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

COVID-19 autumn booster vaccination

Vaccines remain the best line of defence against COVID-19. Protection provided by the vaccine reduces over time, and that's why the autumn booster programme has been introduced.

The Joint Committee on Vaccination and Immunisation (JCVI) has recommended a programme of vaccination against COVID-19 in early autumn. Everyone aged 50 and over, those aged 5 to 49 in a clinical risk group and those aged 5 to 49 who are carers or household contacts of someone who is immunosuppressed are eligible. Health and social care workers and residents in a care home will also be offered the autumn booster.

Can the COVID-19 and flu vaccines be combined into one jab?

No. The available vaccines are for either COVID-19 or flu. Those eligible for a COVID-19 autumn dose and a flu vaccine will receive separate vaccines.

For those eligible to have both vaccines, the NHS will seek to maximise opportunities to co-administer both vaccines where possible, meaning you may have both given at the same appointment.

Find out more about the COVID-19 booster and the seasonal flu jab by watching Dr Oge Ilozue, GP and Senior Clinical Advisor, NHS London Vaccination Programme. In a film recorded specifically for Lymphoma Action, Dr Ilozue addresses many of the questions people affected by lymphoma have been asking. Watch it at lymphoma-action.org.uk/Vaccines

Alternative to the live shingles vaccine now available

Shingles vaccination is recommended for people aged 70 to 79. However, until recently, the only vaccine available in the UK was Zostavax®, based on a live but weakened version of varicella zoster virus (the virus that causes shingles). This is not suitable for people with low immune systems because it could cause shingles infection.

From 1 September 2021, a vaccine called Shingrix® became available for people with lowered immunity. This contains a protein made by the varicella zoster virus, but it does not contain the virus itself, so cannot cause shingles.

If you are eligible for shingles vaccination, you should be contacted by your GP. However if you are between 70 and 79, have not had the shingles vaccine and not been contacted, then get in touch with your doctor to enquire about it.

With thanks to Dr Cathy Burton, Consultant Haematologist at St James's University Hospital, Leeds for answering our questions.





Imaging and lymphoma



Imaging, including X-rays, ultrasound, CT, PET-CT and MRI, is an important tool for helping diagnose lymphoma, showing how well treatment is working and helping with decisions made during treatment.

In a recent podcast, radiologist Dr Manil Subesinghe explains the most common types of imaging used for people affected by lymphoma. He talks about what they are, how they work and gives examples of why someone might have one type of test over another.

He explains: 'When someone comes into hospital with a complaint, it is the job of the radiologist to use scans to find out what is wrong. It is like being a detective, putting together all the information to get an answer. For me, it is enormously rewarding being able to give someone an answer and provide clarity so that the best way forward can be planned.'

Ultrasound scans

An **ultrasound** scan is a test that uses soundwaves (not radiation), to take pictures of the inside of the body. It is commonly used if a lump can be felt in a person's neck, armpit or groin and is easy to get to. An ultrasound scan allows a radiologist to see if the lump looks like an enlarged lymph node. An ultrasound might also be used to help the radiologist find the best place to take a sample of tissue or biopsy.

X-ray

An **X-ray (or radiograph)** is a simple and quick type of imaging using a small amount of radiation (high energy waves/particles that you can't see or feel that pass through the body) to help create a picture of the body. In the UK, Public Health England calculate that on average people are exposed to about 2.7 millisieverts (mSv) of radiation a year. A chest X-ray exposes people to the equivalent of only 2 days worth of the annual radiation dose.

If someone is feeling unwell, such as being short of breath or having a cough, an X-ray is a good starting point to tell if something is wrong. It can also be used for example, to check the position of a central line before using it to give chemotherapy, or to see how healthy the lungs are before and during treatment. Even if nothing appears amiss on an X-ray, there may still be something wrong, and a more complex test like a CT scan may be the next step.

CT scan

A **computed tomography (CT)** scan uses an X-ray tube circling around the body, to create a large number of X-ray images. The images are processed by a computer to generate a series of detailed 3D images that allow the radiologist to see what is going on inside the body.

A CT scan only takes a few seconds but involves more radiation than an X-ray. A CT scan of the chest, abdomen and pelvis amounts to about 7 years worth of radiation.

PET-CT

Positron emission tomography-computed tomography (PET-CT) scans are used a lot in lymphoma and have really made a difference to the way it is treated. PET-CT scans use a radioactive form of sugar to look at the activity of cancer cells; it can help tell where lymphoma has spread to and also how well it's responding to treatment. Combining it with CT scanning means that the scan can also show in detail where in the body the radioactive glucose has been taken up. PET-CT offer two bits of information in one scan. A PET-CT scan takes a long time to complete, on average 90 minutes, and needs people to not eat for 6 hours before scanning.



A PET-CT scan

MRI scan

A **magnetic resonance imaging (MRI)** scan uses a strong magnet and radio waves to make detailed 3D images of the inside of the body. These images are similar in anatomical detail to those from a CT scan. An MRI does not use radiation and so is a safe option if someone is pregnant or has an allergy to contrast agents used in CT.

If doctors think that someone could have lymphoma in their central nervous system (brain and spinal cord) or head, neck or bones, an MRI is a better test than a CT scan to provide detailed information about these areas. However, there are parts of the body, like the lungs, where the information from an MRI scan is not as good as with a CT scan.

An MRI takes about 30-40 minutes to perform. Some people find it claustrophobic and others with certain types of pacemaker can't have an MRI scan due to the strong magnetic field affecting the pacemaker itself.



An MRI scan

Can lymphoma be diagnosed without a scan?

A scan can show where things look abnormal, and suggest either infection, lymphoma or another type of cancer, but cannot tell you with absolute certainty. To find out exactly what is wrong, a sample of tissue needs to be taken and sent to a histopathologist who will look at this sample under a microscope to find out what is wrong.

Very rarely, a doctor can feel a lump, put a needle in it in clinic and send a sample straight to the histopathologist. This doesn't happen often, as doctors like to use scans to guide the needle into the right place and make sure any risk of complication is low.

How is a biopsy taken?

The most common approach to taking a biopsy is with the assistance of ultrasound guidance. This helps locate the lump and assess nearby structures to avoid, such as blood vessels and nerves. This procedure is minimally invasive and uses local anaesthetic to numb the skin. As a result, when the sample is taken, the person can only feel pushing and prodding but no pain. This avoids the need for a general anaesthetic.

When is someone likely to have a scan and are they used in follow-up?

Scans are used if there is a question to answer. They are used in the diagnosis, management, planning and treatment of lymphoma. Scans are commonly used to:

- investigate if something is wrong
- find the best place to take a biopsy
- diagnose and stage lymphoma
- plan radiotherapy treatment
- check response to treatment, by comparing scans taken before, during and at the end of a course of treatment
- find out if lymphoma has come back (relapsed) if a person has symptoms that could suggest it has.

Am I likely to have a scan at follow-up?

Relapse in lymphoma is usually discovered when someone feels there is a change in their body or is displaying symptoms, rather than incidentally on a follow-up scan. That is why it is important for people to know when their body feels right, so that when it doesn't they can flag up a change. A scan is usually carried out to investigate such symptoms.

What can you see on a scan?

As a radiologist, I am trained to know about human anatomy in detail. I need to know what normal looks like to recognise when something is not right.

In a PET-CT scan, for example, I can gather information from the shape and size of organs using the CT part of the scan, whilst the PET part of the scan tells me how well certain organs are working. Importantly, during and after treatment for lymphoma, I can assess whether cancer cells are active or not, which helps me tell the difference between active lymphoma and inactive scar tissue. This is one of the advantages of PET-CT over CT scanning alone.

How long does the report take?

The benchmark I aim for is to report a scan in about 30 minutes, but it can take longer, especially if there is a lot of information to take in. A scan extending from the 'eyes to the thighs' involves looking at over 500 images, each with potentially important information on them, and requiring care and attention. If it is a second or subsequent scan, then I will need to look at previous imaging to see how things have changed, in order to assess how treatment is going.

Some job titles around imaging can sound similar and can be quite confusing. What do they all mean?

A **radiologist** is the person who will look at the images, interpret them and come up with an answer. A radiologist is a qualified doctor who went on to do further training in radiology; I trained for 10 years after finishing medical school before becoming a consultant. I use these years of experience to help me report the scans.

A **radiographer** is the person who you meet when you are having a CT, MRI or PET-CT scan. They are the experts in using the scanners to get the best pictures possible. This is really important as the better the image, the easier it is for the radiologist to interpret the pictures.

A **radiotherapist** is a healthcare professional who operates the radiotherapy machine, which delivers high doses of radiation to kill cancer cells.

Are there times when there is no conclusive answer?

We always strive to get a definitive answer, as any uncertainty is likely to mean subsequent tests and a delay in starting treatment. We look at blood tests and other available information to help our scan reports to be as useful as possible. The best approach is to discuss the case at the multidisciplinary (MDT) meeting. Here the doctor looking after the person may have more information, which might be helpful. We are also able to consult other healthcare professionals outside of the MDT or radiologists who specialise in certain areas of the body, either at the same hospital or elsewhere. There are occasions when we are unable to come up with an answer, and occasionally a repeat scan may be needed.

Is the report shared with the patient?

Imaging reports are usually shared with the clinician who requested the scan. This is usually the doctor looking after the person with lymphoma or suspected lymphoma. It is not more widely shared as the medical words used in the report can be complicated and the report is not in an easy to understand format. However, the doctor will always talk through the results of the scan and what it means with the patient.

With thanks to Dr Manil Subesinghe, Clinical Lecturer in PET imaging and Honorary Consultant Radiologist, King's College London /Guy's and St. Thomas' NHS Foundation Trust. Find out more: Listen to Dr Subesinghe on our podcast: lymphoma-action.org.uk/lymphoma-voices#radiologist

Make a difference

Big Hair Dare



Whether you want to whack on a wig, turn your hair Lymphoma Action purple, big up your beard, lop your locks or go the whole hog and do a head shave, our Big Hair Dare is a fun way to fundraise and support people affected by lymphoma.

You can go solo or ask your school/college/university/workplace to get involved.

Dare to join our Big Hair Dare bunch? You can grab your fundraising pack on our website at lymphoma-action.org.uk/bighairdare, contact the Fundraising Team at fundraising@lymphoma-action.org.uk or give us a call on **01296 619400**.

Our bespoke Kenya Trek

It's not too late to join our group of intrepid explorers in the Great Rift Valley next Spring.

With our Maasai guides, this will be the most incredible adventure, as we trek for over 90km across jagged hills, grassy plains, and awe-inspiring wilderness.

This is a Lymphoma Action exclusive trip, with the opportunity to join other amazing supporters from #TeamLymphoma on a once-in-a-lifetime challenge!

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

Jump into January



Need to get fit this January? Then why not *Jump into January* with a Lymphoma Action physical activity?

You can run, walk, cycle or swim your way to becoming fitter. There's no better 'jump in' than a pool!

Why not challenge yourself by swimming? Set yourself a target of 26 lengths or 26km and we'll provide you with a free Lymphoma Action swimming hat to help you spread the message about lymphoma, the fifth most common cancer in the UK. Or if you want something more challenging, swim 55 lengths or 55km. That's one length/km for every person diagnosed with lymphoma each day. Visit our website to register and get your free Lymphoma Action swimming hat!

Want a bigger challenge? Then what about 1,705 'somethings' as a fitness target - 1,705 people will be diagnosed with lymphoma in the UK this January. You could choose to run, walk or cycle with a target of 1,705. Help us raise money to support everyone affected by lymphoma.

Visit our website for ideas and to register lymphoma-action.org.uk/JumpintoJan

Working with companies that care

Calling all companies!

We work with a wide range of companies, big and small, so if you know of any corporate partnership opportunities please let us know. We'd be delighted to work with you and your team to raise funds, have fun and do something special. We also operate a payroll giving scheme if this is something you or your organisation would be interested in being part of.



Email us at fundraising@lymphoma-action.org.uk



Top Tips: difficulty sleeping?

Many of us have problems sleeping from time to time. We might find it hard to 'switch off' and fall asleep, to stay asleep, or might find ourselves sleeping for a lot of the time.

Having lymphoma can also have an impact on your sleep, from concerns or worries going around your mind, the symptoms of lymphoma such as fatigue or night sweats, or the side effects of treatment.

We asked our closed Facebook Support Group for their 'top tips' and suggestions for those times when they struggle to get to sleep. *Thanks to everyone for their ideas.*

Create the right environment

- Avoid using 'tech' (such as your mobile) in the evening as it can be quite stimulating.
- Avoid having a TV or blue light device on (such as mobiles, laptop or tablets) in the bedroom.
- Use ear plugs if you are disturbed by noise.
- Have a relaxing, uncluttered and dark space to sleep in.
- Use black-out blinds to help if there are street lamps outside, or you are woken by the light outside.
- Using a sleep mask or wearing a soft headband that covers your eyes might help. You can also find headbands that connect to your phone, so you can play relaxing music or white noise (or whatever helps you sleep).
- An electric diffuser with sleep oil might help, and they often have an automatic timer so they turn off after a length of time.
- Spray your pillow with a lavender or special sleep spray, or use on pulse points such as on your wrist or neck. (You may want to check this with your doctor if you have any other conditions or sensitivities.)

Preparing for bed

- Develop a routine: try to go to bed at the same time every evening and get up at the same time each morning.
- Avoid caffeinated drinks after 3pm: try decaffeinated drinks or herbal teas instead.
- Avoid alcohol or try to keep consumption to a minimum.
- If you need a snack before bed try food high in melatonin as this can aid sleep - nuts, eggs, fish, grains, legumes and plant-based foods. Avoid sugar as it's been proven to disrupt sleep.
- Have a tepid shower when it's hot, or a warm lavender bath in the winter; both can be relaxing.
- If you are having night sweats, using a dog cooling mat might help to keep the pillow cool.
- Wear lightweight pyjamas so you don't get too hot, or cosy socks if your feet get cold.

And so to sleep

- There are lots of relaxation and meditation apps available, like 'Headspace'; some of which are free. Search your app store for more information.
- Have the radio on and listen to calming music or an audio book, or the BBC Sounds mindfulness recordings. If you have a voice-controlled virtual assistant, you can ask it to play sounds of nature. They often have a timer to cut off after an hour.
- Try mindfulness: there are courses online.
- Read a few pages of a book until you are sleepy.
- Mental exercises, for example going through the alphabet and naming countries, plants, rivers (it's less boring than counting sheep).



If you still struggle

- Sometimes it can be hard to sleep at night if you've had naps during the day. If you can, try to avoid napping (although relaxing can be helpful).
- Get up, have a warm drink, and read or do a puzzle until you are sleepy, then go through your routine again. Some people find light repetitive physical activity helps and can take your mind off any anxieties. Don't go for a walk or a drive as this can be dangerous.
- Easier said than done, but try not to worry about not sleeping. Worrying can make it harder to get to sleep.
- Remember that some medications, such as steroids, might also affect your sleep or sleep pattern. If you are on medications that you think might be affecting your sleep, talk to your healthcare team about this.
- If you have persistent problems with sleeping, talk to your medical team about what might be helpful for you.
- The Lymphoma Action website has more information about lymphoma and sleep. Read more at lymphoma-action.org.uk/day-to-day#sleep

This information comes from our Facebook community. This is not intended to be medical advice and is not a replacement for advice from your medical team. If you have any Top Tips to share, email the magazine Editor at publications@lymphoma-action.org.uk or join our Closed Facebook Support Group at facebook.com/groups/LymphomaActionSupportUK



Low-grade non-Hodgkin lymphoma: a strange and sneaky illness

Pat shares her experience of extranodal marginal zone lymphoma and the challenge of getting a diagnosis.

I have a non-Hodgkin lymphoma called extranodal marginal zone lymphoma. When I was diagnosed I felt a mixture of alarm and relief. I suspect this is a common sensation felt by people who receive a diagnosis after months, sometimes years, of investigations and odd or distressing symptoms.

I had been fit and well apart from a tiny lump in my mouth and some acute stab-like pains in my scalp, which came and went.

In August 2017, I mentioned the lump in my mouth to my dentist, who referred me to the maxillofacial department at my local hospital. I had a number of visits and was told that it was probably nothing serious; perhaps a salivary duct swelling or a swollen lymph node due to an infection. The registrar reassured me I was not wasting their time as 'lumps and bumps' should always be investigated.

I had a scan and a biopsy from my cheek which revealed some unusual cells. The surgeon who was about to excise the lump examined my mouth, asking me how I was feeling. I replied that I felt fine and didn't think I'd need an operation. He replied rather gravely that I would need further investigation and we talked about the possible outcomes. It dawned on me then that I could be facing what everyone dreads; a cancer diagnosis.

Waiting for that minor operation, my mind went back to earlier that year and some of the signs that something was amiss; a pleasant day out when I had a sudden sharp pinching sensation on my scalp. This had been the first of many acute but brief pains which had continued to bother me for months.

I had gone to my GP and had blood tests and a scalp examination, but they had revealed nothing out of the ordinary. I mentioned my scalp pains again a couple of times, both to another GP and the hospital doctor, but neither expressed a concern that there could be an underlying problem in that area.

There was little I could find on the internet which would support any concerns. These pains on the scalp were an example of what I call 'odd symptoms' which suggest that something might be wrong, but not worrying enough to do more than... well, worry. My hair was thin in one place on my scalp towards the back of my head. I found myself touching it often and wishing it wasn't there. But the pinching pain on my scalp only occurred every few weeks and there didn't seem to be a pattern, so I decided in the end to ignore it.

After surgery to remove the lump inside my mouth I recovered well, but was managing a swollen face and the challenges of eating and drinking. I found out that the biopsy revealed lymphoma cells. I needed more tests to identify what type of lymphoma it was and was referred to the haematology department. I was then diagnosed with extranodal marginal zone lymphoma.

Appointments were being made 'at a pace' and I felt I was in good hands. It was as if I was being carried along a peculiar journey for which I had no plan. Whatever this thing called lymphoma turned out to be, the only thing I could do was wait, and in the meantime, try to find out as much as I could.

Reading about lymphoma when I was first diagnosed was very different to reading about it after treatment. At this very early stage, information seemed theoretical only, not real. I couldn't connect what I was reading with what was happening to me. I expected to understand it all at once, but learning doesn't happen like that. I came across and bought Elizabeth Adler's book *Living with Lymphoma: A patient's guide* (2016 ed). As a neurobiologist who also had a diagnosis of lymphoma her book is full of technical information about the disease.

The Lymphoma Action publication *Low Grade non-Hodgkin Lymphoma* has become my 'go to' reading when I have a quick question. It's taken a long time to take it all in.

After the initial confirmed diagnosis, the good news was that there was no need for any treatment at that time: the condition would be managed by active monitoring or 'watch and wait' where I would receive regular monitoring of my general health and any symptoms. The not so good news was that the disease could become active again and reappear anywhere in the body, although it was explained that the most likely place would be the location of the original tumour; in my case the cheek or face area.

'I think of lymphoma as a strange and 'sneaky' illness; it can hide and mimic other conditions. One option could be to embrace it as a moody and somewhat unpredictable friend; someone who you don't hear from for a long time and then reappears needing your full attention...'

I had a meeting with a very helpful nurse specialist who said I could contact her if I ever needed to between appointments, which were roughly every three months. Feelings of anxiety arose as I felt for lumps and bumps before each appointment, but much of the time I was able to forget about the diagnosis altogether.

2018 was a good year. There were trips to see family and friends, city breaks in London and Amsterdam, a new grandchild, a nephew's wedding and a house move. My partner of 18 years and I settled into our new home and started to enjoy long walks in the countryside and I was able to indulge my life-long love of painting in my new garden studio.

Lumps in my neck started to develop in February 2019. At about the same time, I had noticed strange visual disturbances similar to those before a migraine headache. It was as if I'd been staring at the sun and could see the afterglow. My optician assessed my vision and urgently referred me to an ophthalmologist at my local hospital a few days later. I was told that my vision seemed normal, which was confusing, but my concerns were referred back to my haematologist.

I had an MRI scan to investigate whether there was lymphoma in the central nervous system. This revealed thickening in an area on the underside of the scalp, which I was told could be a benign tumour called a meningioma. My medical team recommended I start low-dose chemotherapy, due to the increased size of the swellings in my neck, forehead and scalp. In the meantime, another MRI was scheduled and my consultant told me that neurology had recommended a biopsy be taken from my scalp. This biopsy revealed that there was lymphoma in my scalp; also extra nodal marginal zone lymphoma. Low-dose chemotherapy was planned.

Although the various swellings on my head and neck were obviously growing, I felt well with no discomfort. Low-dose chemotherapy was planned to start a couple of months later and at the time I agreed with this non-urgent approach.

In November while driving, I had found myself unable to tell whether I was pressing the correct pedal and felt unsafe to drive. It was a strange sensation, as if my brain didn't quite know where my foot was. Something similar had happened earlier that year while on a walk. A few days later, I was upstairs folding laundry when I suddenly felt light headed, my leg gave way and I sank to the ground.

My leg began to shake and I felt as if I was losing control. I was just able to call for help before starting to shake violently. An ambulance arrived very quickly and took me to the local hospital. I went straight into A&E and then to a medical admissions ward. Two days later I met my new consultant haematologist who explained that an MRI scan confirmed that the lymphoma had breached the blood brain barrier, causing a swelling in my brain. I found out that this swelling, or brain oedema, was what had previously been thought to be a possible meningioma (a tumor that arises from the meninges, the membranes that surround the brain and spinal cord). My understanding is that the lymphoma on my scalp had moved through the meninges via the lymphatic vessels in the cranial cavity.

Further tests and scans took place and 3 days later I started a course of R-CHOP chemotherapy, with a plan for intrathecal methotrexate and two courses of intravenous methotrexate. R-CHOP is an intensive and aggressive protocol of six three-weekly doses of three chemotherapy drugs, one monoclonal antibody and steroids. Although I had one period in hospital with a mouth infection, I found the treatment bearable and am immensely grateful to all the NHS staff involved. Two and a half years after treatment, I am in clinical remission, having made a good recovery and with no identifiable lasting neurological damage.

I am aware that my slow-growing extranodal marginal zone lymphoma may still have surprises in store, but I feel better prepared for any new symptoms and any treatment required. Hopefully, as more understanding of lymphoma emerges, people will feel more confident in asking questions when they know something is wrong. It is after all a strange and sneaky illness.

Leaving a gift to Lymphoma Action

Last year we were gifted a generous legacy from a long-time supporter, Carol Taylor. Her sister, Lynne Taylor, reflects on why Carol chose to leave a gift in her will to Lymphoma Action.

'I hope my efforts will enable many more people to benefit from their knowledge, care and comfort.'
Carol (pictured right)



In 2020 Carol Taylor and her sister, Lynne, took part in our Bridges of London walk. Together they made their way around the 7-mile route, along with 300 other #TeamLymphoma supporters. For Carol this was a tremendous achievement, as she was suffering from myelodysplasia as a result of many rounds of chemotherapy and a failed stem cell transplant. This was not the first time Carol had fundraised for Lymphoma Action, having taken part in a swimathon, held a music event and even written a poetry book.

As well as taking on a number of fundraising events for Lymphoma Action, Carol was also a member of the Portsmouth Lymphoma Action Support Group and was part of the Buddy service. Lynne recalls how these services provided a great deal of help to Carol and her family and why Carol wanted to also remember Lymphoma Action in her will.

'Carol wanted to be able to give something back to Lymphoma Action after the support they had given her for more than 20 years.'

We are always honoured when a legacy has been left to us, and being able to speak to close family and friends to find out why is such a privilege.

With a gift in your will, you will be helping us to be there for future generations affected by lymphoma. If you would like to find out more about leaving a gift in your will, please contact us on **01296 619400** or fundraising@lymphoma-action.org.uk. For more information please visit www.lymphoma-action.org.uk/legacy. Please note that we are unable to provide legal advice.

Support for family, friends and carers: focus on Benefits

There can be a lot of pressure on family, friends and carers supporting someone with lymphoma. We know from calls we receive at Lymphoma Action that many people are unaware of the benefits that may be available for carers.

Eleanor Spink, Welfare Benefits Caseworker for Citizens Advice, based at the Maggie's Centre in Southampton, explains some of the benefits available to carers. This is not an exhaustive summary and Eleanor emphasises that anyone who wants to find out more should get in touch with Citizens Advice or a charity that supports people in claiming benefits, such as Maggie's Centres or Macmillan.

Am I a carer?

There are lots of ways you can be a carer for somebody. If you support someone with one or more of the following you might be considered a carer:

- washing
- dressing
- cooking
- accompanying or taking to appointments
- managing bills
- shopping
- emotional support.

Benefits you might be entitled to as a carer

The main benefits we are going to focus on in this piece are those specific to carers:

- Carers Allowance
- Carers Credit
- Carers Element of Universal Credit.

Carers Allowance

Carers Allowance is the main benefit carers receive and at time of writing, it entitles the recipient to £69.70 per week. You need to spend 35 hours a week caring for someone to claim the benefit, the person **you care for** must be receiving a disability benefit.

There are a number of benefits they may be claiming (for example, Disability Living Allowance, Constant Attendance Allowance, Armed Forces Independence Payment, Child Disability Payment, Adult Disability Payment) but the most common ones are the following.

- Personal Independence Payment (PIP) – a disability benefit for people of working age. They must be receiving the daily living component of PIP.
- Attendance Allowance – which is the same as PIP for people of state pension age.

Only one person can claim benefits for caring for one individual at a time. If there are more people providing care, then it is usually the person who gives the most care who would make the claim.

Carer's Allowance eligibility criteria:

- You are 16 or over.
- You spend at least 35 hours a week caring for someone.
- Your earnings are £132 or less a week after tax, National Insurance and expenses.
- You've been in England, Scotland or Wales for at least 2 of the last 3 years (this does not apply if you're a refugee or have humanitarian protection status).
- You normally live in England, Scotland or Wales, or you live abroad as a member of the armed forces.
- You're not in full-time education.
- You're not studying for 21 hours a week or more.
- You're not subject to immigration control (if from EU, you usually need to have settled or pre-settled status).

If you are on State Pension, you cannot get the full amount of State Pension and Carers Allowance together. They are overlapping benefits, so if your State Pension is less than £69.70 per week, it would be topped up with the Carers Allowance.

If you get State Pension and Pension Credit (which is a means tested benefit for people over state pension age), your Pension Credit might go up if you are a carer.

How to apply for Carers Allowance

You can apply online at gov.uk/carers-allowance/how-to-claim

Alternatively, you can print the form (see link below), fill it in and send it in the post. gov.uk/government/publications/carers-allowance-claim-form

The forms can be quite confusing and there are services available to help you fill them in, such as Citizens Advice, Maggie's, or anywhere that provides benefits advice.

Carers Credit

Carers Credit is broader than Carer's Allowance. To be eligible you must:

- be over 16 and under state pension age
- care for someone for at least 20 hours a week.

Like with Carers Allowance, the person you care for must be receiving a disability benefit (see under Carers Allowance) such as PIP or Attendance Allowance. However, if the person you are caring for does *not* receive one of these benefits, you can complete a 'Care Certificate' which forms part of the application. It is a separate page to explain why the person is not on these benefits, but why you still require Carers Credit.

Carers Credit is not an amount of money you receive, but is a National Insurance Credit. These are important for state pension to ensure you get the full amount when you reach state pension age. Essentially Carers Credit will pay your National Insurance contributions so you have no gaps if you have to take time off work to care for somebody. It is the same principle as if you have a child under 12.

How to apply for Carers Credit

You can find the 'Carers Credit application form' at publishing.service.gov.uk. You need to print off the form and post it. Alternatively call 0800 731 0297 to request a form.

Carers Element of Universal Credit

With Universal Credit you get a standard amount of benefit, but there are some circumstances that mean your Universal Credit will be increased. For example, if you have children, if you pay rent or if you have limited capability to work. Being a carer may also qualify you for an additional amount, and this is called the 'Carers Element'.

To qualify, you have to meet the general Universal Credit conditions, plus the required Carers Element conditions, of which the main ones are:

- You have less than £16,000 in savings.
- Your income level qualifies you for Universal Credit. This depends on lots of things and I recommend using an online 'benefit calculator'. (*More details on next page.*)
- You provide 35 hours of care each week.
- The person you care for is in receipt of Attendance Allowance or PIP, Disability Living Allowance or Child Disability Payment, the Daily Living Component of PIP or Armed Forces Independence Payment or Constant Attendance Allowance, Industrial Injuries Benefit or War Disablement Pension.

Universal Credit is means tested, so your earnings and income will affect how much Universal Credit you are entitled to overall. If you are already on Universal Credit and you become a carer, you can inform them by writing a note in the journal reporting a change of circumstance.

One thing to be careful of before making an application for any benefits

Claiming carers-related benefits including those in this article, can affect the benefits of the person you are caring for, such as:

- a severe disability premium like Income Support, Income Based Job Seekers Allowance, income related Employment and Support Allowance and Housing Benefit
- the 'severe disability' element of Pension Credit
- Council Tax reduction.

Most people's benefits are moving over to Universal Credit, but it is important to check with the person you are caring for, as they could lose some of these benefits if you make a claim.

Always seek specific advice through Citizens Advice or another charity offering benefits advice.

The Equality Act 2010

The Equality Act 2010 legally protects people in Britain from discrimination in the workplace and in wider society. There are nine protected characteristics:

- age
- disability (which includes anyone with cancer)
- gender reassignment
- marriage and civil partnership
- pregnancy and maternity
- race
- religion or belief
- sex
- sexual orientation.

Under the Equality Act 2010, it is illegal to discriminate against someone because of their responsibilities as a carer to someone with a disability.

The Equality Act 2010 applies to anywhere you are treated differently such as work, education, shopping, using public transport or public facilities.

What is a Carers Assessment?

A Carers Assessment is free and is something that might make life easier. At the Carers Assessment, healthcare issues or any need for care can have a needs assessment done by the local council at the same time. It could recommend:

- someone to take over caring so you can take a break
- gym membership and exercise classes to relieve stress
- help with taxi fares if you don't drive
- help with gardening and housework
- training on how to lift safely
- local support groups, so you have people to talk to
- advice about benefits for carers.

Contact adult social services at your local council and ask for a Carers Assessment.

Where can I get advice specific to my situation?

The following organisations all have online **benefit calculators** that might be useful. You enter your personal information and they will tell you what you are entitled to.

- Online benefit calculator [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators)
- Turn2us (which also has a benefit calculator) [turn2us.org.uk](https://www.turn2us.org.uk)
- Entitledto [entitledto.co.uk](https://www.entitledto.co.uk)
- Policy in practice [policyinpractice.co.uk](https://www.policyinpractice.co.uk)

Citizens Advice

You can access benefits information from Citizens Advice in a number of ways:

- Visit your local Citizens Advice office.
- Use the Citizens Advice national Adviceline on 0800 144 8848.
- Visit www.citizensadvice.org.uk

Charities like Maggie's ([maggies.org](https://www.maggies.org)) and Macmillan ([macmillan.org.uk](https://www.macmillan.org.uk)) are able to advise on benefits as well.



Note: Information in this article is correct as of September 2022.



Let down by my body yet enormously proud of it

Hayley talks about her diagnosis and treatment for Hodgkin lymphoma

I was 31, working as a freelance copywriter and living with my partner David. Around Christmas 2020 I noticed that even a sip of alcohol gave me pain in my shoulder and my back. I thought this was really odd, so I Googled it (which I know you really shouldn't do), and something that came up a lot was 'lymphoma'.

I did nothing about this for 2 or 3 weeks, and had no other symptoms at that time, but it troubled me, so I decided to go to my GP. Blood tests were organised which came back normal. I really didn't want anything to be wrong, so these results reassured me.

Looking back, I didn't say anything about my suspicions of lymphoma to my GP. In my mind I worried that by saying something I would be undermining him. But if I had mentioned something, would he have told me about the symptoms of lymphoma?

'Don't be afraid to say what's on your mind.'

About six months later I started to develop other symptoms, like itching without a rash. This came and went and it wasn't until a few months later, when I found an enlarged lymph node under my armpit, that I went back to my doctor. By now it was November 2021, and I am still cross with myself that I hadn't joined up the dots and that I delayed returning to the GP.

My doctor referred me to the breast clinic because of where the lump was located. I had a biopsy taken and waiting for the results was a really worrying time. By now I had convinced myself that I had lymphoma, so when the diagnosis was Hodgkin lymphoma it wasn't a shock. In many ways it was a relief to know what was wrong, rather than living with uncertainty.

Having a clear diagnosis meant I could now do more research, but this time I made sure I only looked at trusted sites like Lymphoma Action and the NHS. I encouraged my family to look at the information available on these sites so that they understood more clearly about Hodgkin lymphoma.

The haematologist explained that it is a very treatable type of cancer, which was reassuring. I was offered three treatment options; I wasn't expecting to have a choice and found it rather overwhelming. I could have ABVD chemotherapy, escBEACOPP or take part in a clinical trial which was investigating whether an immune checkpoint inhibitor given before chemotherapy is a safe and effective treatment for people with untreated advanced classical Hodgkin lymphoma.

My instinct was to enter the clinical trial, and I liked the idea of being involved in something that could help others in the future. But my lymphoma was at an advanced stage and I just wanted to get going with treatment as soon as possible. Taking part in the clinical trial felt like it would delay things which didn't feel right for me.

I had a conversation about fertility before treatment began and it was explained that ABVD was more likely to preserve my fertility. Although I'm fairly sure I don't want children, I think it is an important discussion for someone of my age to have.

I was treated with ABVD chemotherapy (doxorubicin (Adriamycin®), bleomycin, vinblastine and dacarbazine). I coped incredibly well with minimal side effects. So much so, that I wondered if the treatment was working. I had long hair and was advised to have it cut, but decided not to. I let it fall out gradually, but eventually gave in and cut it. I also struggled with fatigue and quickly recognised a routine of when I would feel most tired. As a freelancer, I decided to continue working, and although fatigue meant I had to pace myself - and certainly didn't feel at full capacity - it gave me something else to focus on, and I feel it helped me mentally.

'My body was pretty astounding.'

I had a PET scan after two cycles of ABVD and as a result the bleomycin component part of the treatment was removed for the rest of my treatment. A CT scan at the end showed I was in remission. It was at this point that I cried for the first time. Throughout treatment I was pragmatic and took a 'let's just get on with this' approach. It was once treatment finished that all the emotions rushed in and I felt lost.



Everyone around me was incredibly happy and relieved that the treatment was successful and wanted me to share the joy. I just didn't feel like celebrating, and was struggling with the psychological effects of what I had been through.

My body coped well, even though towards the end of treatment, fatigue was increasing and I was needing to sleep for longer.

My treatment was during COVID and it could have been easy to isolate myself. I live with my partner David and at first I felt really cautious, not wanting to see anyone else for fear of picking up an infection or COVID.

My family live nearby and once treatment had finished, family and friends expected me to return to how things had been beforehand. But nothing was the same, and I just wanted to keep myself safe. My clinical nurse specialist said I shouldn't cut myself off entirely, so gradually – and ever so carefully – we have started to see people. We choose to meet outdoors and if we are eating out, choose an outside table.

Simultaneously I feel let down by my body, but also enormously proud of it.

My body let me down by becoming ill, but the strength I have has been amazing.

Unfortunately, a PET scan three months after the completion of treatment showed that my lymphoma has returned.

Although I am now facing more treatment, I feel confident in my body to handle whatever is to come.



Hodgkin lymphoma: did you know?

- Hodgkin lymphoma is rare, with around 2,100 people diagnosed with it each year in the UK.
- There are two main types of Hodgkin lymphoma based on how they look under a microscope: classical Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma, which is much rarer.
- It can occur at any age, although most people diagnosed are between the age of 15 and 34, or over 60.
- Hodgkin lymphoma affects slightly more males than females and can develop in people of any ethnic background.

An update from Tara, our new Policy and Public Affairs Advisor

'It's been an exciting and busy time to join Lymphoma Action. A big part of policy work involves understanding what's going on across the government, NHS and other blood cancer charities, and my role involves influencing any of this work that will affect lymphoma patients.'



Lymphoma Action have been working closely with One Cancer Voice, Cancers52 and the Blood Cancer Alliance to vocalise key issues in cancer services, and make sure these are being addressed. For example, we have worked in collaboration with the One Cancer Voice coalition of charities to ensure we keep cancer care at the top of the government's agenda.

We have contributed to several Health Technology Assessments (HTAs) for different lymphoma and COVID treatments. This means gathering experiences of those who are affected by certain types of lymphoma and giving this as evidence for why the drug should or shouldn't be used. This helps decision makers understand what treatments the NHS should invest in, ultimately resulting in better treatment options for those diagnosed with lymphoma. We are currently responding to an assessment of Evusheld, (a preventative COVID treatment) drawing on the evidence and experience of the wider global lymphoma community to make as strong a case as we can for Evusheld being made available for those with lymphoma.

Since I joined Lymphoma Action, the results of the 2021 Cancer Patient Experience Survey (CPES) have been published. It's great to see that so many people took part, and we'd like to thank anyone who did. These surveys are an invaluable source in helping to shape policy and services for people affected by lymphoma.

Results showed that almost half of lymphoma patients speak to a GP three or more times before receiving their diagnosis. Additionally, around 30% of lymphoma patients did not fully understand their diagnosis or felt they were not told about their cancer sensitively.

While evidence shows that we've still got a long way to go, there are several exciting projects in the works that will help patients receive earlier and faster diagnosis. We are working closely with our colleagues in the NHS by giving them insight from our clinical experts, supporters and those affected by lymphoma to support their initiatives. This includes their work on Non-Specific Symptom pathways, which looks at improving how we can faster diagnose people who come forward with vague symptoms. In addition, their clinical audit for non-Hodgkin lymphoma will provide evidence to improve treatment and outcomes for patients.

So it's been a busy first few months in the Team! Ensuring that the voice of those affected by lymphoma is heard remains our priority and we hope to see some progressive change.'

Christmas is around the corner

Light a star this Christmas

The Christmas period is a time to reflect and remember. You can remember a loved one and let their memory shine on this Christmas, by lighting a star for all those affected by lymphoma and help us shine a light on the UK's fifth most common cancer.

To light a star in memory, visit our dedication page lymphoma-action.memorypage.org/lightastar2022, call the Fundraising Team on 01296 619419, or email fundraising@lymphoma-action.org.uk or use the QR code here.



Christmas Shop

Giving a present to someone means a lot and a Lymphoma Action gift means double the giving, as you will be making a difference to all those affected by lymphoma! Our online shop has lots of great gifts including our fabulous branded dog bandanas and new matching teal bobble hat. There are some great stocking fillers, and seeds of thanks, which pop nicely into Christmas cards.

Go to our website to see the full range lymphoma-action.org.uk/Christmas

Don't forget when you are Christmas Shopping online you can also sign up to support people affected by lymphoma at no extra cost with:



Don't leave your Elf on the shelf this Christmas!

Why not get your little ones involved in some elf fun?

At Lymphoma Action we're getting the whole family involved in an Elf Run. We will provide an 'Elf pack' including an Elf hat – we just need those all important naughty and nice Elves to take part!



This event is great for schools, so if you have any connections with schools in your local area please consider registering for our Elf Run this December.

Full details can be found on our website lymphoma-action.org.uk/Christmas

Festive Fashion Day – Thursday 15 December



Dress up like a fairy, don your Christmas jumper, adorn yourself with tinsel or simply wear some Christmas socks. Whatever you want to do is OK with us on Lymphoma Action's 'Festive Fashion Day'.

In the office, at school, or with friends and family, decorate yourself in order to raise awareness (and a few pennies) this Christmas for Lymphoma Action. Why not hold a competition and give a prize to the most festive?

Full details found on our website lymphoma-action.org.uk/FestiveFashion

Still time to enter...

Win some extra cash this Christmas! There's still time to take part in our 2022 Prize Draw. Tickets were sent out with our previous *Lymphoma Matters* magazine or can be bought online at lymphoma-action.org.uk/prizedraw Tickets must be received by 12pm on Wednesday 30 November to be included in the draw. All money received after that date will be treated as a donation.

September was Blood Cancer Awareness Month...

This year people from across the UK have been working exceptionally hard to raise awareness of lymphoma.

From sharing stories on radio, in national magazines and local newspapers, to manning stands in community venues and hospitals, you have spread the word about lymphoma. People across the country have shared their posts on social media, telling the country what lymphoma is, the signs and symptoms to look out for and how we support people affected by lymphoma.

You've also pulled out all the stops when it comes to fundraising for us. From crocheting, to baking, to walking, running and cycling, to dying your hair purple, through to gala dinners and auctions, you've been busy ensuring that we can continue with our vital work. So, a massive THANK YOU from the bottom of our hearts to all of you for all you have done this September.



Online support – going from strength to strength

Since the start of the pandemic, we have provided Online Support Meetings. We can see the impact these have had; the number of people we are able to reach across the whole UK and the additional meetings we are able to offer. We also see the access they give to people who could not have attended a face-to-face support group.

We have currently decided not to return to face-to-face Support Groups but to continue developing our suite of Online Support Meetings in the four nations.

I have found Online Support Meetings supportive, refreshing, reassuring and informative every time.

We are excited to be trailing additional special interest meetings based on where people are in their treatment and for rarer lymphomas. Our bi-monthly topic specific meetings will also become monthly. These have covered topics from fatigue to stem cell transplants and we've found that people have really appreciated the opportunity to share similar experiences with others. We are also planning 'Introduction to Online Support Meetings' sessions to provide a 'tour' of our support services.

We recognise that not everyone can, or wants to, access support online and are considering every service closely to offer something for everyone. We're delighted that we'll be reintroducing face-to-face Live your Life self-management workshops to run alongside the online workshops. We also look forward to the National Conference being a live event in 2023 (see back cover).

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.

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. 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

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

Lymphoma Action National Conference

Reconnecting the lymphoma community

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

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



Tickets £30. Book online: lymphoma-action.org.uk/NationalConference

Got a question? Email conferences@lymphoma-action.org.uk
or call 01296 619412.

Coming to the conference?

Why not make a weekend of it and join us for Bridges of London?

Support people affected by lymphoma and walk the iconic bridges of London or a bridge in your local area.

Visit lymphoma-action.org.uk/Bridges23 for details.

Join
#TeamLymphoma
for Bridges of Britain and
London
14 May 2023

