

lymphoma matters

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Lymphoma
action



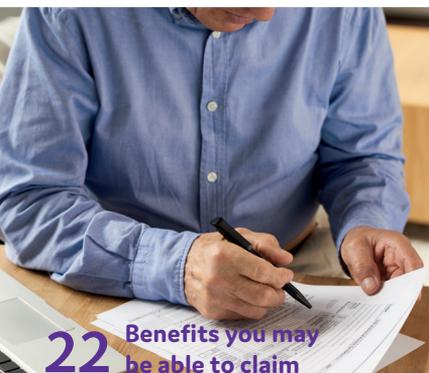
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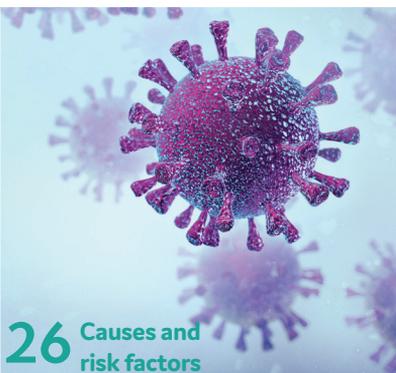
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for 35 years, 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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- Visit lymphoma-action.org.uk/Donate
- Call us on 01296 619419

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Making the most of old and new

Welcome to your latest edition of *Lymphoma Matters*.

Thanks to your generosity this magazine can be sent out free of charge to nearly 25,000 people and I hope you will agree that it's an informative and important publication. *Lymphoma Matters* is available in both print and electronic format, and from the feedback we receive we are reminded of how valuable traditional, printed materials are at a time when we are doing so much digitally.

Ropinder Gill
Chief Executive

Important information on vaccines and boosters can be found on page 6.

As you read the magazine you'll notice that we continue to provide updates on COVID-19 where it has an impact on people living with lymphoma, as well as our usual trusted information and support. And as we plan for 2022 there is so much more we want to achieve. We want to make our services more accessible than ever, consider restarting face-to-face events, as well as developing our digital services while continuing to provide our traditional printed books. We are currently in the 'messy middle' of the pandemic trying to prioritise our resources.

To help our resources go even further we continue to collaborate with others, making our voice stronger as we advocate for people affected by lymphoma. We do this by being part of the Blood Cancer Alliance, coming together with the One Cancer Voice coalition of charities and with Cancer52.

Despite the challenges, and with your help, we promise to keep providing expert information and support and to keep pressing for better diagnosis, treatment and care, especially against the backdrop of the pandemic.

We are delighted to welcome our new Director of Services, Dallas (see page 4), and we are excited by the new energy she will bring to the charity and our lymphoma community. Thank you for being part of that community.

Ropinder Gill
Chief Executive



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

Lymphoma Action welcomes new Director of Services

We are delighted to welcome Dallas Pounds as our Director of Services at Lymphoma Action.

Dallas joins Lymphoma Action after eight years as Chief Executive of Royal Trinity Hospice. She has also worked as an Executive Director at The Terence Higgins Trust, and is a nurse by background, having worked in the NHS for 25 years before joining the charity sector.

'I am very excited to be joining Lymphoma Action, and supporting the charity in delivering and developing services that support people living with lymphoma and those close to them' says Dallas. 'I worked as a nurse in haematology many years ago, so I am really looking forward to being part of this great team who provide such vital services to people affected by this type of blood cancer.'



'We are delighted that Dallas is joining our Senior Management Team' adds Ropinder Gill, Chief Executive. 'It's really exciting to have someone joining at this time who has so much experience within the NHS and the health sector, and who shares the Charity's commitment to delivering inclusive services.'

Spring prize draw

Our 35th Anniversary Prize Draw took place on 1 September. Congratulations to the winners, and many thanks to everyone who took part.

Your money goes towards supporting people affected by lymphoma. The full list of winners can be seen at lymphoma-action.org.uk/PrizeDraw

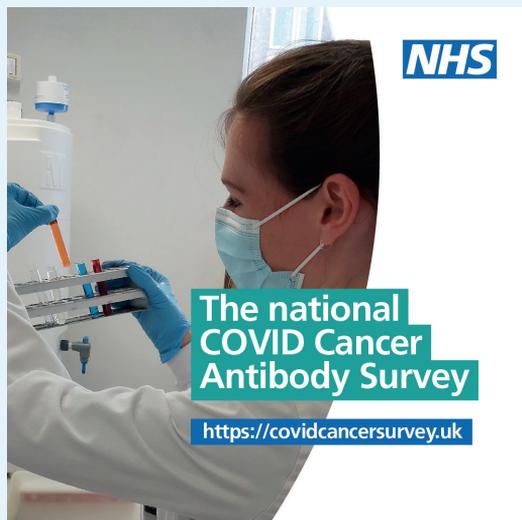


Get involved in The National COVID Cancer Survey

The National COVID Cancer Survey is measuring COVID antibody levels in people with cancer to find out more about what level of antibodies is enough to provide protection against COVID-19.

You can sign up to take part if you live in England and you've either been diagnosed with cancer in the past year, or you are being treated for cancer. This includes people on maintenance therapy.

If you are eligible, you can sign up online at covidcancersurvey.uk You will be taken through to the NHS Test and Trace website to order an antibody testing kit free of charge, which is sent to you in the post with instructions. You send your sample back to a lab to be tested.



As well as measuring your antibody levels, the survey will use information from NHS databases to monitor the outcomes of people with different antibody levels. This will help find out what level of antibodies is enough to provide protection against COVID-19, so that doctors can advise people with cancer on their individual level of risk and what precautions they might need to take.

Sign up at covidcancersurvey.uk

The Lymphoma Action range of books

Don't forget we produce a range of 16 books that are available to download or order for free. Our books are written for people with lymphoma, and their families, friends and carers, to help them better understand their diagnosis, treatment and life beyond lymphoma.

Download: lymphoma-action.org.uk/Books

Order a copy free of charge:

lymphoma-action.org.uk/Shop





Update on vaccinations and boosters

The annual flu jab

The flu vaccine is given free on the NHS to people who meet any one of a number of qualifying conditions. The list includes people over 50, frontline health, social care workers and people with certain health conditions, which includes lymphoma.

You are recommended to have an annual influenza vaccine or 'flu jab' if you have lymphoma, if you have had your spleen removed (splenectomy), or 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, some evidence suggests 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.

Third dose of COVID-19 vaccines for people with severely lowered immunity

The Joint Committee on Vaccination and Immunisation (JCVI) has recommended a programme of third COVID-19 vaccine doses for people who had severely weakened immune systems at the time they had their initial vaccine doses, as they may not have responded to vaccination as well as others.

Those eligible for a third dose include many people affected by lymphoma:

- People with Hodgkin lymphoma or high-grade non-Hodgkin lymphoma who were on treatment or within 12 months of achieving cure at the time they had their initial COVID-19 vaccinations.
- People with low-grade non-Hodgkin lymphoma or chronic lymphocytic leukaemia (CLL) who were under follow-up at the time of their initial COVID-19 vaccinations. This might include some people on active monitoring (watch and wait), if their immune systems are severely weakened. Specialists will consider the individual circumstances to decide whether or not people on active monitoring are likely to need a third dose.
- People who had a self (autologous) or donor (allogeneic) stem cell transplant in the 2 years before they had their initial COVID-19 vaccinations (or more than 2 years for people who are still immunosuppressed or have graft-versus-host disease). Note: people who had a stem cell transplant or CAR T-cell therapy after their initial COVID-19 vaccinations should be completely revaccinated 3 to 6 months after treatment.
- People who were on immunosuppressive chemotherapy or radiotherapy at the time of their initial COVID-19 vaccinations or within the previous 6 months.

- People who had high-dose steroids in the month before their initial COVID-19 vaccinations.

GPs and hospital specialists will identify those eligible for a third dose. If you are eligible, you should have got a letter from your hospital specialist or GP telling you how to get your vaccination. If you think you are eligible for a third dose and you haven't received a letter, contact your hospital specialist or GP for advice.

Am I likely to respond to a third dose if I didn't respond to the first two?

Clinical trials are looking into this at the moment. Early evidence suggests that some people with lowered immunity have an improved immune response after third dose of COVID-19 vaccination. However, some people still may not respond. It is important to keep taking precautions to reduce your risk of developing COVID-19.

Is this the same as a booster dose?

Not quite. Booster doses aim to help your immune response to vaccination last as long as possible. This programme is called a 'third primary dose' and aims to improve the initial response to vaccination in people who may not have responded well to their first two doses.

The COVID-19 booster vaccination

The government are rolling out the booster programme and you can book your COVID-19 booster if you have been contacted by the NHS and are aged 50 and over or are aged 16 and over with a health condition that puts you at high risk from COVID-19. You'll only be able to book an appointment for a booster dose if it's been at least 6 months since your 2nd dose of the COVID-19 vaccine.

Alternative to the live shingles vaccine now available

The shingles vaccination is recommended for people aged 70 to 79. However, until recently, the only vaccine available in the UK (Zostavax®) was 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.

People aged 70 to 79 who may be eligible for Shingrix® vaccine instead of the live vaccine include:

- people with Hodgkin lymphoma or high-grade non-Hodgkin lymphoma who are less than 12 months since achieving cure

- people with low-grade non-Hodgkin lymphoma or chronic lymphocytic leukaemia (CLL) who are under follow-up
- people who have had a self (autologous) or donor (allogeneic) stem cell transplant in the last 2 years (or more than 2 years for people who are still immunosuppressed or have graft-versus-host disease)
- people who have had immunosuppressive chemotherapy or radiotherapy in the last 6 months
- people who have had moderate-to-high-dose steroids for more than 10 days in the past month.

You have two doses of Shingrix®, at least 8 weeks apart, given as an injection. It is a one-off course of vaccination, so you do not need an annual booster.

If you are eligible for a 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.



Information correct on 1 October 2021.
Check our website for latest updates.

With thanks to Dr Cathy Burton,
Consultant Haematologist at St
James's University Hospital, Leeds
for reviewing this information.



Lewis never wanted to be without my support

Sophie shares her experience of caring for Lewis, who was diagnosed with high-grade non-Hodgkin lymphoma.

Lewis and I met online nearly a decade ago, before online dating was even a thing. We've both always been strong characters, and although our early stages were turbulent to say the least, something just clicked. Just six months after meeting, he quit his job, left his house share, and moved into my family home. A big part of our fast-paced, early relationship was instantly discovering many shared interests and a dream to travel.

Having not long graduated from university, and Lewis a newly qualified plumbing and

heating engineer, we got full time jobs, and spent a year saving hard to turn our dream into a reality. Yet throughout these twelve months, Lewis repeatedly became unwell with a series of nasty chest infections. They began with cold-like symptoms but always manifested into more serious infections; green phlegm, a dry, recurring cough and feeling so unwell that he missed repeated weeks of work, each time taking longer to recover. The trips to the doctors mounted up, and he was prescribed course after course of antibiotics. After the fourth trip, we began to question what was going on, and wanted some answers as to why a previously fit, healthy, rugby-playing 22-year-old was continually becoming so ill.

Lewis was given a wide variety of diagnoses; from tonsillitis right through to hay fever. Satisfied with none of these, we finally managed to get him a blood test at our local doctors' surgery. The conclusion was that at some point, he had contracted glandular fever, as the virus was remnant in his blood test results. This discovery was made shortly before we were due to leave for Australia after a year of saving and planning.

It's a very difficult time to look back on, as we were so full of hope that plenty of sunshine and fresh air would improve his health, and we tried our best to put any worries to one side. Over the course of three months spent travelling around in our little campervan, Lewis displayed numerous tell-tale signs of a cancer diagnosis, but this was so far off our radar as two young adults in our early twenties.

His appetite dwindled – it was 40 degrees, that's normal, right? He lost a substantial amount of weight – lack of appetite, it's boiling hot after all! Night sweats, soaking him through – it's 40 degrees remember? He became breathless, fatigued, his fitness failing him. After surfing, he repeatedly complained of tightness in his chest, feeling as if he was being strangled. It wasn't until my mum flew out to Sydney to visit us, that reality began to dawn on us all. We had a wonderful couple of weeks together, but it was repeatedly interspersed with her concerns, and she made us promise to get Lewis straight to the doctors. She hadn't seen him for three months, and could see the drastic difference in his health compared to when we had left the UK.

We took Lewis to a walk-in doctors surgery in an attempt to finally get some answers.

We were taken seriously, and Lewis was immediately sent for an urgent chest X-ray. The doctor gave us an envelope with the X-ray images and told us to go straight to a hospital in Sydney where late that night, we were told Lewis had cancer. Two days later, we were on a flight back to the UK for him to begin chemotherapy immediately. After a barrage of blood tests, scans and biopsies, he was diagnosed with primary mediastinal diffuse large B-cell lymphoma, a type of high-grade non-Hodgkin lymphoma.



Our entire lives, plans and dreams felt as if they had been snatched from under our feet. Lewis spent the next two years enduring treatment after treatment, trying to combat his aggressive form of lymphoma. We had to watch as our friends and family continued with their lives, whilst our weeks, months and then years became a blur of endless days in hospital wards. I felt helpless watching the person I love become a shell of himself; withstanding treatment after treatment, infection after infection, pain after pain. It was a lonely, isolating and utterly numbing time. I felt all I could do was to be there for him throughout every second of every day. As we had both quit our jobs before flying to Australia, I had no other commitments, so I spent every day by his side. I never missed a hospital appointment, I slept curled up on chairs in A&E, and on camp beds in his hospital ward.

It was a hard time. It became very difficult to let other people into the world we were living in, so we stopped doing so. Lewis rarely felt well enough to have friends spend time with him in hospital, and even family visiting became a rarity as he found it very difficult to cope with too much noise, or people asking lots of questions. I'm an inherently introverted person, so we both lost a lot of friends during that time. I had no emotional energy to dedicate to others, communication was hard; people knew the facts, but had no understanding of how either of us were feeling.

We were in our own little bubble, hiding away when things were bad, and putting on a complete front during any rare social occasions. Because of this, we were, and still are, totally reliant on each other. A couple that discusses every finite detail, runs every little thing past each other, whether we need to or not. In October Lewis will be five years in remission and we are slowly finding independence from each other.

My advice would be to let other people in. It's a hell of a lot to handle by yourself.

Friends won't always know what to say, when to be there, or when to give you space. Family may not understand when you can't handle another question, or when you wished they had asked about one thing in particular. But nine times out of ten, they wish they knew. So try to tell them.

This June, we returned from 18 months spent travelling around Australia and New Zealand. Throughout 2020, in a year where time stood still for so many, and plans and dreams were put to one side, we were finally living ours.



It felt as though the universe had gifted us precious days we thought we would never get back. We spent over a year visiting every corner of Australia. Lewis bought two beautiful surf boards, spent hours in the water, not once complaining of a tight chest or difficulty breathing. We went back to the walk-in doctors, back to the hospital where he was diagnosed. We sat in the sunshine, and took the time to remember all that we had been through; all of the bad, and then how far we had come; all of the good.

We're back in the UK now, arriving home on our own terms this time. We have a beautiful Golden Retriever who we couldn't wait any longer to be reunited with, and we're now planning what's next. We're looking for somewhere to settle, somewhere much closer to our support network this time, but hopefully some place wonderful to bring children into the world. Lewis' treatment means we aren't able to do that naturally, but that means nothing as long as he's here to be a father. We aren't sure what's next just yet, but we have health and happiness, and that's just about all we need.

Wonderful treks

Join #Team Lymphoma for one of our wonderful treks, have a new adventure and raise money for people affected by lymphoma.

Hebridean Way Adventure – September 2022

This 9-day challenge will give you the chance to experience the unique island environment, culture and wildlife that makes the Outer Hebrides so enchanting. From Castlebay, Barra to Stornoway on Lewis, our Hebridean Way trip allows you to discover the best sections of the full walk in just 9 days! Watch out for eagles, seals and dolphins on your way, as well as for archaeological remains along the trail. **Sponsorship target** (covers accommodation and food): **£2,500** Find out more: lymphoma-action.org.uk/HebWay

Our bespoke Kenya Trek in the Great Rift Valley – Spring 2023

Join us and our Maasai guides on the most incredible Kenyan adventure, as we trek for over 90km across the jagged hills, grassy plains, and awe-inspiring wilderness of the Great Rift Valley. This is a Lymphoma Action exclusive, bespoke trek with very limited places: join a handful of other amazing supporters from #TeamLymphoma for this once-in-a-lifetime challenge! **Sponsorship target** (which includes all costs): **£3,500** Find out more: lymphoma-action.org.uk/Kenya

We can help you with your fundraising. Contact fundraising@lymphoma-action.org.uk

Festive Fashion Day – Friday 3 December

Get on your Christmas jumper, adorn yourself with tinsel in the office, at school, or with friends and family and donate to Lymphoma Action. Why not hold a competition and give a prize to the most festive? Find out more:

lymphoma-action.org.uk/FestiveFashion



Virtual Santa Run – Sat 4 and Sun 5 December

Be part of something amazing this year and run or walk 5K at your own pace, in your preferred place with family or friends to raise much needed funds for Lymphoma Action at the same time as spreading festive cheer and having fun! Registration is £5 and you'll get a Christmas mask and hat. Find out more: lymphoma-action.org.uk/VirtualSanta

Our fabulous fundraisers

We are always amazed at our wonderful supporters. Here are just a few of our fabulous fundraisers and the amazing challenges they have set themselves!



Melinda asked people to name her gorgeous kitten



6-year-old Evie running 6 miles to nanna's house to raise funds for us



David raised £3,490 by cycling 355 miles from London to Paris this September



Alana skydived with her dad to support her best friend going through chemotherapy

Blair and Dionne completed three walking challenges to celebrate Blair's 12 years being lymphoma-free



Feel inspired?

Check out our website lymphoma-action.org.uk/fundraising-from-home or contact us at fundraising@lymphoma-action.org.uk or call **01296 619419**

Surinder's story



Nurse consultant Surinder shares her experience of lymphoma

I am a nurse consultant in primary care. In November 2018, I noticed I had raised lymph nodes in my neck, and could feel lumps which felt very small and mobile. At the time I thought it was just my lymphatic system doing its job. I was also experiencing dizziness and vertigo, but as I have spondylitis, which is inflammation in the spinal bones or vertebrae, I thought it was as a result of that condition.

The lumps on my neck didn't go away, so I asked my colleagues to check them out. They said that if they didn't go after a short period I should have them investigated.

I was referred to ENT (ear, nose and throat) who thought they were fatty lumps. Although my blood tests were fine, the ENT consultant

decided to do a biopsy. I also requested that the lumps be removed and checked.

The results of the biopsy suggested I had nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

I had a CT/PET scan, which showed I had loads of tiny clusters around my collar bone, some by my spleen and some in my chest. My diagnosis was confirmed as NLPHL, stage 3S.

I was shocked at the extent of the disease, as I had expected just a couple of nodes to be affected. My husband was with me and was enormously supportive. The doctor explained that NLPHL was slow-growing and that my prognosis was good.

Telling my family was difficult. We are an Indian family, and I knew some of the family would think this would mean the end of my life. I'm sure other people will identify with this. We had lost my mum to cancer 2 years beforehand, so I could understand their fears. I needed to tell them at the right time and in the right circumstances. We went out for a meal, but all I can recall of that evening was the tears. So many tears. But in my own mind I was convinced I would get through this.

My consultant explained I would start R-CHOP chemotherapy straight away, although with this cancer there could have been a period of active monitoring (watch and wait). Although radiotherapy can be an option for NLPHL, they said it was not appropriate in my case.

After the first chemotherapy my long dark hair just blew out. For me it really is a major part of my identity, and emotionally I found this really difficult. It was a very clear indication of what I was going through – to myself and also to my family. I think I handled the treatment pretty well, and tried to take a 'I've just got to get on with this' approach. I was fortunate that I didn't get any infections that could have delayed my treatment and managed to complete the course of chemotherapy within five months.

After the third chemotherapy cycle the scan indicated that the lymphoma had all gone. My consultant said that it was a brilliant response. I hoped they would say I could stop the treatment at this stage, but they made it clear I needed to complete the next three cycles. I knew that would be the case, and part of me felt very positive, but I can honestly say that was the longest time of my life.

I finished my treatment in June 2019 and was back at work the following month.

For my mental wellbeing I really needed to get back to some sort of normality.

One problem I had was that the backs of my legs felt very stiff, something that caused me problems from early on in the chemotherapy. As a result I have reduced my hours as my legs simply won't make it past 4.30pm.

A year and a half later, I discovered a cyst on my back, which I decided to have removed because I was having aches and pains more often. I also had rheumatology screening which showed raised markers for rheumatoid arthritis and connective tissue disease. I wonder whether these things could be caused by the chemotherapy?

As a nurse consultant, I found the experience has changed the way I practice in some ways.

As a result of my experience, I appreciate the need to keep people updated regularly and feel I have a greater understanding of their worries and anxieties. I also have a far greater knowledge of lymphoma!



Photographer: Sam Bagnall



The importance of physical activity for health, and its effect on cancer-related fatigue

Senior occupational therapist Jennifer Woods and specialist haematology and oncology physiotherapist Aimee Green talk about the benefits of physical activity. They focus on cancer-related fatigue, considering exercise and other strategies to help manage this challenging side effect.

The benefits of physical activity

Any movement that uses energy, both moderate and vigorous, improves health. Recent guidelines by the UK Chief Medical Officer recommend being physically active every day, stating that any activity is better than none and more is better still.

If you are not normally physically active, anything you do will have a huge benefit. In fact, the greatest benefits can be seen in people who are not normally active and who start to introduce small amounts of activity into their routine. Aim to reduce time spent sitting or lying down with activity, such as going into the garden if you have one, or going up and down the stairs.

Benefits of physical activity following a diagnosis of lymphoma

There are many benefits to being physically active, including:

- improved mood
- reduced anxiety during treatment
- improved sleep
- strengthening bones
- alleviating joint pain.

When is the best time to be active?

We are often asked: 'When is the best time for me to start exercising; is it immediately after diagnosis, just before or during treatment or after treatment?' The answer is: 'All of those times.' Try and be physically active throughout the treatment pathway and beyond, as that way you will get the most benefit.

At diagnosis

When you're first diagnosed, you may feel you have lost some control. Doing physical activity can help you prepare physically and mentally, giving you back some control. It will help with your recovery after treatment, reduce side effects or make them less severe, and improve your mood.

Always talk to your healthcare professional about any plans to get active before or during treatment. They can give you advice on where to start.

During treatment

Being physically active during treatment can help to reduce side effects, such as poor appetite, constipation and fatigue (more on that later in the article). It can also improve your sleep, reduce anxiety and improve your mood.

In addition, it can help to build strength, keeping you physically well during your treatment.

If you are not normally active, start slowly and gradually. It can be helpful to **set goals** for physical activity, but it is important to keep them realistic for you. You know what you can manage and if you try to do too much it will be difficult to stick to. Start very gradually and build up slowly.

If you are normally very active, then we advise that you exercise at a lower intensity during treatment because of some of the side effects of treatment. You can then gradually build it up again. Depending on your treatment, there are some communal activities that you should be careful with at this time, such as going to the gym or going swimming. This is because you might have a very low white cell or neutrophil count which will put you at increased risk of infections.

Seek advice from your healthcare professional about any exercises you should be avoiding.

After treatment

There are many benefits to exercising beyond cancer treatment. Exercise can help to reduce late side effects of treatment and lower the risk of developing new or recurring cancers. It can also help reduce the risk of other medical conditions such as stroke, heart attack and osteoporosis.

What are the barriers to physical activity?

Most of us know that exercise is helpful, but there may be barriers to increasing physical activity, particularly when you are going through treatment.

Loss of fitness during treatment, pain, loss of concentration, change in weight, low mood or self esteem or loss of confidence, can make it really hard to do physical activity.

If any of these factors are preventing you from doing exercise, speak to your healthcare team who may be able to refer you to services that can help.

Focussing on cancer-related fatigue

Cancer-related fatigue is the most common side effect people with cancer experience, but it is also the most under-reported, despite being so difficult for many people.

A formal definition of cancer-related fatigue is: 'A common and persistent and subjective sense of tiredness related to cancer treatment or the disease itself and it usually interferes with normal function.' As healthcare practitioners, what we often hear is: 'I feel like someone has pulled out the plug and all my energy has gone.'

Cancer-related fatigue is different to tiredness. You expect to feel tired after a busy day or a late night, but after rest or a good night's sleep, you regain some of your energy.

With cancer-related fatigue it can come on all of a sudden, without any warning and it is not alleviated with rest and sleep.

80% of people undergoing cancer treatment, either with chemotherapy or radiotherapy in an outpatient setting experience fatigue.

What are the signs?

Cancer-related fatigue can be present with both physical and cognitive symptoms. These include feeling tired and weary, for some it can impact on concentration, making it hard to remember things like dates, read books or follow instructions. It can also have an impact on mood, often making people feel irritable.

A lot of people describe being frustrated because they expected to return to the level of activity they had before treatment, but instead cancer-related fatigue is affecting their ability to do things.

What are the causes of cancer-related fatigue?

There are a number of causes, including the lymphoma itself and treatment. It can also be caused by side effects of treatment, pain, insomnia, stress and low mood.

Can anything be done about cancer-related fatigue?

There is no magic pill that can eliminate cancer-related fatigue and sometimes we, as health professionals, have to try several different approaches. Cancer-related fatigue can be persistent, but there are things that can help.

When should I seek help, and is there anything that can improve this?

Cancer-related fatigue is very subjective. People will experience fatigue in different ways and it will affect their lives in different ways too. Think about it on a scale of 0-10, where 0 is when you have lots of energy and 10 is when you are feeling completely exhausted.

I think if you are scoring above a 4, then it is time to think about talking to your healthcare team about this symptom, to explore ways that they can support you.

Without fatigue, people start the day with their energy levels at 100%, but as the day goes on the energy levels dwindle. After a night's sleep, the energy levels start at 100% again.

Someone struggling with fatigue does not start the day with 100% energy. They often start at about half that, and as a result they run out of energy much quicker. But there are some tactics to make that reduced energy stretch a little further.

The first thing to look at is **energy conservation**. There is a strategy called the 'Three P's', although you'll notice we've included four!

1. Planning

Plan your time. You can do this on a daily basis, but in our experience it works well to think in full weeks. That way you can include essential activities, such as follow-up appointments, as well as activities you really want to engage in, such as social events.



Consider when you have the most energy, and where you can fit in rest breaks to make it possible to do the things you want to. Also consider triggers that might be making your fatigue worse. A fatigue diary is a really helpful tool for this.

2. Pacing

Take your time and don't try to do things at the pace you used to; remember you are trying to make your energy go further.

3. Prioritising

Think about what you need to do and what you would like to do. Are there things that can be put off or that you can ask someone else to do? It can be difficult to ask, but family and friends are often only too willing to help. Prioritising can help you to preserve energy for the things you would like to do.

4. Permission

Sometimes people want to do things the way they did before their diagnosis. Give yourself permission to do things differently and accept that it's OK. Be kind to yourself.

Enhancing your energy levels

There are ways of enhancing energy levels, such as physical activity, nutrition and sleep. It might be overwhelming to try to change everything at

once, so pick an area where you can most easily make adjustments, or that you would most like to try.

Exercise

As we said earlier, this doesn't have to be conventional exercise; it can include gardening, housework, walking, yoga or running. Choose something that is achievable and will bring you the most enjoyment.

Nutrition

The nutrients in a balanced diet can increase your energy levels, though we understand that if you are feeling unwell or fatigued this may be difficult. Here are some tips that may help with nutrition:

- drink plenty of water
- consider eating small meals and snacks throughout the day, so you're not faced with a large meal that seems unmanageable
- look at ways of minimising the effort of cooking, such as using frozen vegetables rather than cutting and chopping fresh
- consider asking family or friends to make meals for you to put in the freezer
- try batch cooking when you have energy.

Sleep quality

Sleep affects quality of life and wellbeing, and disruptive sleep can worsen fatigue.

There are small changes you can make to improve the quality and quantity of sleep you are having:

- Stick to a routine by going to bed at the same time, and getting up at the same time.
- Limit the amount of caffeine, sugary drinks, energy drinks and alcohol from late afternoon so your body isn't alert in the evening.
- Think of the environment you are sleeping in; block out light or have low lighting.
- Screens can increase your alertness and make it difficult to unwind, so try to eliminate them about an hour before you go to bed.
- Incorporate some kind of relaxation into your bedtime routine that works for you, such as mindfulness, listening to relaxing music or reading.

There are some useful relaxation and sleep packs, on the NHS website. There are also apps that may be useful, such as *Headspace* and *Calm* to look into.

With thanks to
Aimee Green, specialist
haematology and oncology
physiotherapist and
Jennifer Woods, senior
occupational therapist
both at The Christie,
Manchester.

Do something wonderful...

Leaving a gift in your will is a simple way to make a huge impact, as well as a wonderful way to safeguard our services for the future.

Legacy income has raised over half a million pounds for the charity. We are hugely grateful to our past supporters whose legacies have helped us through the pandemic.

Whatever the size of your gift, your legacy will make a difference.

What is a legacy or a gift in your will?

After making sure your loved ones are taken care of, you might decide to remember a charity in your will. There are several types of gifts: a cash gift (or a 'pecuniary legacy'); a percentage of your estate (or a 'residuary legacy') or a specific gift (like an item of jewellery).

Any gift, even just a small percentage of your estate, will ensure that we can be there to support people affected by lymphoma – not only those diagnosed, but friends, family and carers too.

How do I leave a gift?

We strongly advise that you use a qualified solicitor as they will be able to advise on the legal formalities for making a will as well as tax implications (charitable gifts are exempt from inheritance tax and can be used to reduce your overall tax burden). Writing your will doesn't have to be expensive and you can find a solicitor in your local area.

Further information can be found on the Law Society website: www.lawsociety.org.uk

The most important bits of information to include, if you decide to remember Lymphoma Action in your will, are our name, address and registered charity number:

Lymphoma Action, 3 Cromwell Court, New Street, Aylesbury, Buckinghamshire, HP20 2PB
Registered charity No 1068395 (England and Wales) SC045850 (Scotland).

Further information can also be found on our website at lymphoma-action.org.uk/legacy

How can I find out more?

If you would like to let us know about your legacy, or discuss leaving a gift in your will, please contact us on **01296 619400** or email s.knowles@lymphoma-action.org.uk



Corporate Donations

We work with a wide range of companies, so if you know of any opportunities please let us know, or you can always raise donations during zoom meetings. It's easy to do – you just need to download the app at www.pledge.to/zoom-app

Light a star this Christmas

The Christmas period is a time to reflect and remember – light a star for all those affected by lymphoma and help us shine a light on the UK's 5th most common cancer. Remember a loved one and let their memory shine on.

To light a star in memory of a loved one visit our dedication page lymphoma-action.memorypage.org/lightastar2021 call the Fundraising Team on 01296 619419 or email fundraising@lymphoma-action.org.uk

Christmas is coming...

We have lots of activities to get involved in this Christmas to help ensure no one has to face lymphoma alone. Find more information on our website lymphoma-action.org.uk/Christmas



Check out our marvellous Christmas cards, now available to order, and don't forget when you are Christmas shopping yourself you can also sign up to support people affected by lymphoma at no extra cost while shopping online with:





Photograph posed by model

Claiming benefits for people living with cancer

A diagnosis of lymphoma creates many challenges. Treatment, appointments and all the information that comes with these things can be overwhelming. Benefits are not often on the forefront of people's minds, but a cancer diagnosis can have a real impact on work and finances. Jagdeep Gill, Lead Benefits Advisor at Maggie's Southampton understands that people don't always know what benefits may be available for them and acknowledges some people can find it difficult to talk about finance and benefits. However, she would urge people with lymphoma to consider these issues early on, as most benefits cannot be claimed retrospectively.

Personal Independence Payment (PIP)

Personal Independence Payment (PIP) is a disability benefit which can help with some of the extra costs, such as personal care and mobility needs, if you have a long-term physical or mental health condition. It is for working age people (aged 16-67) and is non means-tested, which means it does not take savings, capital or household income into account. You cannot claim PIP until you have a recognised need for 3 months and are likely to have that need for another 9 months.

You can make the initial claim by calling the PIP new claims line on 0800 917 2222. You will be sent a form to complete, although you are likely to have to have a medical assessment before a decision is made.

You will not be entitled to PIP if your treatment is over a short period of time, but people having longer periods of treatment or are experiencing long-term side effects may be eligible. If you are claiming PIP and your circumstances change at any time, you must report it to PIP on 0800 121 4433.

Disability Living Allowance (DLA)

Disability Living Allowance (DLA) is a similar benefit to PIP but for children under the age of 16. From age 16, a young person can claim PIP. DLA looks at personal care and mobility for children. A form will be sent to you to complete with some questions centred around school for example. A decision will be made without any need for a medical assessment.

Attendance Allowance (AA)

Attendance Allowance (AA) is a disability benefit for people over pension age (aged 67 and over). It covers personal care, such as washing and dressing, but it does not include a mobility component. It is a non-means tested benefit but to qualify you need to have had the care need for at least 6 months. AA is straightforward to claim. You will be sent a form to complete and a decision will be made without any need for a medical assessment.

All the above disability benefits are disregarded as income for means-tested benefits and can be paid in addition to other benefits you may be claiming: there are some exceptions to PIP.

Carers Allowance (CA)

This benefit is for people caring for someone who is in receipt of a disability benefit such as PIP, DLA or AA and their award includes either the care or daily living components. You have to spend at least 35 hours a week caring for the disabled person. It is non-means-tested and the amount you can claim is £67.60 per week. People who do not have savings or other income may want to apply for the means-tested Universal Credit to top up their Carers Allowance.

If you are caring for someone who you do not live with then it is always best to check whether it will affect his or her benefits before making a claim for Carers Allowance.

New Style Employment and Support Allowance (ESA)

New Style Employment and Support Allowance (ESA) is a sickness benefit for people who are ill or have a health condition or disability that limits their ability to work. You may be able to get New Style ESA if you are unable to work while self-isolating because of COVID-19. It is a contributory benefit, which means you may be able to get it if you have paid or been credited with enough National Insurance contributions over the last 2 tax years before the year you're claiming in.

If you have been self-employed, you will need to have paid class 2 National Insurance contributions to claim this benefit. If you have only paid voluntary contributions, you may not be able to claim New Style ESA. If you are unsure what contributions you have made, it is best to apply and The Department of Work and Pensions (DWP) will be able to check whether you are eligible.

You will have to go through an assessment period where you provide fit notes to the DWP. You will then be sent a questionnaire to complete. The DWP may contact your doctor or consultant before making a decision.

If you are receiving treatment for cancer, you would be found unfit for work. The DWP will place you into one of two groups.

The first group is the Work-Related Activity Group; this element will not entitle you to receive any additional top-up of money and your contribution-based entitlement will end after 12 months. The Support Group is the second element; you will receive an additional £39.40 per week on top of your basic allowance of £74.70 per week and your contribution-based entitlement will continue for an indefinite period.

If you are unhappy with which group you are placed in then you can look to challenge the decision, but would need to do so within 30 days from the date of the decision.

You can claim New Style ESA in addition to PIP.

Contractual Sick Pay (CSP)

If you are employed and have had a cancer diagnosis and needed treatment, you may be entitled to Contractual Sick Pay, whereby you can receive full pay for a period (please refer to your employment contract for full details). If that is the case, that would be your only source of income, although you could potentially claim PIP if you are going to be off for a long period of time.

Statutory Sick Pay (SSP)

If your employer does not pay Contractual Sick Pay, then they can pay you Statutory Sick Pay (SSP), which is £96.35 per week for 28 weeks. To qualify your weekly average earnings should be more than £120 per week. If SSP runs out after 28 weeks, or your employer is not able to pay SSP, then you can claim New Style ESA.

If you are self-employed, the default is New Style ESA so long as you have paid the right class of National Insurance contributions (that is Class 2 for self-employed people).

Other benefits that might be relevant

Pension Credit

This is a benefit for pension-aged people. It is means-tested, depending on income and savings. Pension credit works to top up your income; you can backdate a claim up to 3 months so long as you have met the qualifying conditions throughout that period.

Council Tax reduction

This is a means-tested benefit for working age and pension age people who are on a low income and have savings below a certain amount. Each local authority will have a different scheme in place.

Universal Credit

This is a means-tested top-up of benefit or main source of benefit. It is for people of working age (18-67; those 16-18 are not usually eligible). If you are part of a mixed-aged couple, this is where one person is above pension age and the other person is below pension age, you will have to claim Universal Credit until both of you reach pension age. Universal Credit has replaced these benefits for most people; Housing Benefit, Income Support, Income-based Job Seekers Allowance, Income-based Employment and Support Allowance and Tax Credits.

Universal Credit can assess whether you are unfit for work in the same way as New Style ESA. Therefore, if you are self-employed and not eligible for New Style ESA you can make a claim for Universal Credit, depending on household income and savings.

Sources of help and support

- Citizens Advice ([citizensadvice.org.uk](https://www.citizensadvice.org.uk)) have a breadth of information on benefits.
- Turn 2 Us ([turn2us.org.uk](https://www.turn2us.org.uk)) have an A-Z on benefits including a benefit calculator.

- Entitled To (entitledto.co.uk) have a benefit calculator.
- GOV.UK pages also have information on most benefits and details on how to apply.

How to apply for benefits

If you think you may be eligible for benefits, it is best to get a benefit check. Maggie's Centres, Citizens Advice and Macmillan all offer help and support free of charge. They can also guide you through filling out the forms. There are instructions on the GOV.UK website on how to make a claim, but they can be quite complex. For Carers Allowance and New Style ESA, you can make the initial claims online, but for most of the other benefits, you are likely to have to make a telephone call.

With most sickness and disability benefits you will have to complete long forms with questions asking about your needs and what you can and cannot do (you may have difficulty standing or lifting for example). These can take around 2 hours to complete, depending on how significant your care needs are. Maggie's, Citizens Advice and Macmillan can all help you fill out these forms.

Other forms of support

Prescriptions

As someone diagnosed with cancer, you are entitled to free prescriptions. Ask your GP for a medical exemption certificate which will entitle you to free prescriptions for 5 years.

Parking charges

Many hospitals have parking concessions for people having cancer treatment. Ask your nurse, or the information desk, if there are any concessions at your hospital.

Wigs

Synthetic wigs are free of charge on the NHS in Scotland, Wales and Northern Ireland. In England, synthetic wigs are free on the NHS for children, people on certain benefits and people on a low income. If you don't meet the criteria for a free wig, you might still be eligible for a subsidised wig from your hospital. Ask your nurse specialist for details. You could also speak to Macmillan as they have bursaries for wigs.

If you buy a wig privately, you shouldn't have to pay value added tax (VAT). This applies to anyone who has lost their hair because of cancer. Ask the company for a VAT exemption form when you buy the wig.

Financial matters (debt management)

Citizens Advice can provide debt advice and can refer you to a team who can go through options for you, including income maximisation. Government brought into force something called the 'Breathing Space Scheme' where you can put a hold on most creditors for 60 days, with most interest and penalty charges frozen, and enforcement action halted. This offers a small window of opportunity for people to seek debt advice.

Working from home

Clinically vulnerable people are no longer required to shield and can be asked to go back into work. Your employer should talk to you about what measures are in place as they have a legal responsibility to reduce any risks to your health and safety within the workplace.

With thanks to Jagdeep Gill, Lead Benefits Advisor at Maggie's Southampton for explaining benefits available for people living with lymphoma.



Photograph posed by models

Causes and risk factors for lymphoma

Although this article looks at some of the factors that might contribute to the development of lymphoma, in most cases there is no known cause.

If you have lymphoma, it's not because of anything you did or didn't do. You can't catch lymphoma and you can't give it to anybody else.

Lymphoma is a type of cancer that develops when white blood cells called lymphocytes grow out of control. This happens if the DNA inside a lymphocyte changes in a way that tells it to stop responding to the signals that usually keep it under control. DNA changes (mutations) happen all the time. Most of the time they're completely harmless, but once in a while they can affect critical genes. One DNA change on its own is not usually enough to cause lymphoma. It usually takes a number of different changes before a cancer starts to grow. In most cases it's not known what causes these changes.

Most probably happen by chance, but in some cases a cause can be identified. There are also some risk factors that might make you more likely to develop the DNA changes that lead to lymphoma.

Risk factors for lymphoma

Having one or more risk factor for lymphoma means you are a bit more likely to develop lymphoma than someone with no risk factors. But remember, lymphoma is rare. Risk factors for lymphoma include age, family history, certain infections, a lowered immune system and autoimmune conditions among others.

Age

Lymphoma can develop at any age, but most types of non-Hodgkin lymphoma are more common in older people. This is because genetic changes in your cells (mutations) tend to build up throughout your life. Some of these changes can lead to lymphoma. Hodgkin lymphoma, however, is most common in people aged between 15 and 40.

Family history

Your risk of developing lymphoma is slightly higher if you have a close relative (parent, brother or sister, or child) who has had lymphoma or another type of blood cancer. This might be due to lots of small genetic changes which you inherit that all increase your risk of lymphoma slightly.

Weight

Having a body mass index of over 30 (obesity) increases your risk of developing many types of cancer, including Hodgkin lymphoma, non-Hodgkin lymphoma and chronic lymphocytic leukaemia (CLL).

Keeping a healthy lifestyle by maintaining a healthy weight, exercising regularly and eating a healthy diet can reduce your risk of many health problems.

Previous cancer treatment

Most people who've been treated for another cancer do not develop lymphoma. However, some chemotherapy drugs used to treat other types of cancer, including other blood cancers, might increase your chance of developing lymphoma in the future. Exposure to radiation, including radiotherapy for other cancers, can also increase your risk of developing lymphoma.

Breast implants

Breast implant-associated anaplastic large cell lymphoma (BIA-ALCL) is caused by having textured breast implants. Scientists think it might be caused by an inflammatory reaction to the implant. It typically develops 8 to 10 years after having the implant. Most people with breast implants do not develop BIA-ALCL – but everyone who develops BIA-ALCL has breast implants. In many cases, removing the implants cures the lymphoma.

Infections

There are some infections that can increase your chance of developing lymphoma. There are a few reasons for this:

- Some viruses infect lymphocytes – the type of cell that grows out of control if you have lymphoma. Occasionally, these viruses can cause changes to the DNA of the cells so they become cancerous.
- Some infections make your immune system too active. This means your body is constantly making new lymphocytes, which increases the chance of changes developing in their DNA. Occasionally, these DNA changes can lead to lymphoma.
- Some infections weaken your immune system. This makes it harder for your body to fight off other infections, including infections that might be linked to lymphoma.

Many of the infections linked to lymphoma are very common. Most people who have these infections do not get lymphoma. Scientists don't know why some people who have certain infections get lymphoma while most don't.

Viral infections

A number of different viral infections have been linked to lymphoma. They include:

- **Epstein-Barr virus (EBV)**: a very common virus that can cause glandular fever which infects B lymphocytes. EBV stays in your body, but is normally kept under control by your immune system. People infected with EBV have a higher chance of developing some lymphomas, but the vast majority of people who have EBV do not get lymphoma.
- **Hepatitis C virus (HCV)**: a virus that infects the liver. It has been linked to nodal marginal zone lymphoma, splenic marginal zone lymphoma, lymphoplasmacytic lymphoma, and diffuse large B-cell lymphoma (DLBCL). Effective treatments for HCV are available.

- **Human T-lymphotropic virus type 1** (HTLV-1): HTLV-1 is a rare virus in the UK that infects T lymphocytes. It is strongly linked to a very rare lymphoma called adult T-cell leukaemia/lymphoma.
- **Human herpesvirus 8** (HHV-8): HHV-8 infects lymphocytes. It is linked with a very rare form of lymphoma called primary effusion lymphoma (PEL).

Bacterial infections

Bacterial infections linked to lymphoma include:

- ***Helicobacter pylori***, which can cause gastric MALT lymphoma.
- ***Chlamydia psittaci***, which causes a rare lung infection called psittacosis. It's spread by birds, including pet birds like parrots. Infection with *Chlamydia psittaci* is linked to MALT lymphoma in the tear ducts and around the eyes.
- ***Campylobacter jejuni***, a common cause of food poisoning. It usually gets better on its own without treatment. It has been linked to MALT lymphoma in the small bowel.
- ***Borrelia burgdorferi***, the bacteria that causes Lyme disease, an infection spread by ticks. It might be linked to MALT lymphoma in the skin.
- ***Moraxella Catarrhalis***, a bacteria which can cause chest infections, is linked to an uncommon form of Hodgkin lymphoma.

Lowered immune system

If you have a lowered immune system, you are less able to fight infections, including infections that increase your chance of developing lymphoma. The two particular conditions that lower your immune system and have a higher risk of lymphoma are:

- **Human immunodeficiency virus** (HIV)
- **Post-transplant lymphoproliferative disorders** (PTLDs).

Autoimmune conditions

Autoimmune conditions are illnesses that develop when your immune system mistakenly attacks your own body. Most people with autoimmune conditions do not develop lymphoma. However, some are linked to a higher chance of developing certain types of lymphoma. This might be because autoimmune conditions can cause long-term activation of the immune system. Another possible reason is that people with autoimmune conditions are likely to be on medicines that dampen their immune system. Both of these factors can contribute to the development of lymphoma.

Several autoimmune disorders might increase your chance of developing lymphoma.

- **Sjögren's syndrome**
- **Hashimoto's thyroiditis**
- **Coeliac disease**
- **Rheumatoid arthritis** and **systemic lupus erythematosus**

Eczema is an inflammatory skin condition that is linked to non-Hodgkin lymphoma. Scientists are studying eczema to work out whether or not it is an autoimmune condition.

Chemicals

Being around high levels of industrial chemicals, solvents, weedkillers and insecticides are possible risk factors for developing lymphoma. Hair dyes might also be a risk factor, although modern hair dyes seem to be safer than those used in the past (pre-1980s). However, the evidence on all these chemicals is limited and scientists aren't sure if there is a link with lymphoma or not.

With thanks to Dr Graham Collins, Consultant Haematologist and Lymphoma Lead, Oxford University Hospitals NHS Foundation Trust, for reviewing this information.

Diversity and Inclusion: 2021 update

Our goal is to support everyone affected by lymphoma, but we know we don't reach everyone. In 2020, we put in place our Diversity and Inclusion framework to provide us with a roadmap to making our charity and services as accessible and inclusive as possible.

One outcome of our framework was a research project we conducted earlier this year, looking into the health inequalities that occur for people affected by lymphoma.

We carried out an online survey, in-depth interviews, a literature review and spoke with our Insights Panel to improve our understanding of the needs of different communities and the barriers that may be stopping us from reaching people.

The interviews in particular gave us some valuable insights into the unique experiences of people who were, in some cases, struggling with everything from financial pressures to difficult family circumstances, to language barriers.

Although the practical, emotional and social impact of lymphoma varies from one individual to another, we want to ensure that we find ways to help and support **everyone** affected by this type of blood cancer.

We are committed to doing more to address these issues and to working collaboratively alongside other organisations, such as Blood Cancer Alliance and Cancer52, to look at the health inequalities that affect the blood cancer community.

This will be an ongoing process and there is a lot that still needs to be done, but we have started to implement some of the recommendations from the Health Inequalities Research project. We started with a website accessibility audit and looking at how we can improve the information on our website. With the help of our supporters we can make sure that we reach and support more people and those who may need us most.



It became clear that groups of our lymphoma community found it difficult to access our services due to:

- having a disability in addition to their lymphoma
- finding it difficult to know what was available
- feeling that our services were not especially aimed at them – this was apparent in young people and those from some ethnic minority backgrounds.



Grounds for optimism

Gerry talks about his experience of HIV-related lymphoma

In 2001 I was diagnosed with HIV (human immunodeficiency virus). Although things have changed a lot since then, it appeared in my case I was classified as a 'slow progressor'. As a result, I was simply monitored routinely to check that my T-cells didn't drop too low.

Nowadays antiretroviral therapy (ART; drugs that keep HIV under control) would be started straight away, but I didn't actually start them until 2013.

Although the HIV diagnosis was a shock, I managed to get on with my life, and in my mind I sort of 'parked it'. In fact, over many years I was fairly healthy, with no opportunistic infections and only one brief spell in hospital, and I felt I had been enormously lucky. I continued with a normal life, even living and working abroad for a while.

In 2018, when I was 58, I suddenly had a sharp pain under my arm and found a lump. I went to my GP, which led to many tests and in the August I was diagnosed with primary effusion lymphoma stage 4. This is a very rare and aggressive form of non-Hodgkin lymphoma.

What I hadn't realised, or perhaps had been told and hadn't absorbed, was that people with HIV long-term are more likely to develop cancer. When I received the initial news about the rarity and aggressive nature of my form of non-Hodgkin lymphoma, I was really shocked.

It was the second time in my life I had received life-changing medical news.

With my cancer diagnosis, I was advised against searching the internet about my condition. I simply couldn't avoid doing so, but what I found was bleak and doom-laden and often out of date. At times I found this overwhelming, and initially at least, it hindered my hopes for getting better with treatment, despite constant reassurance from my doctors.

If I had read that some people were, in fact, doing well several years later, it would have filled me with far more optimism. I would have realised that one day things could be better again.

As I have HIV, my treatment was shared between my HIV treating team and my oncologist. For me, this shared care approach worked really well, and it helped me achieve the optimum results from the treatment.

Between August and December 2018, I had six courses of EPOCH chemotherapy (etoposide, vincristine, doxorubicin, cyclophosphamide and prednisone) which was very debilitating. Going through intensive chemotherapy is not great for your immune system, and with HIV it meant I was even more vulnerable to infections, and had to be extremely careful.

I faced many of the common side effects such as constipation, huge fatigue and uncomfortable peripheral neuropathy. My Hickman® line got infected and I clearly recall one awful night when things seemed very dark indeed, and I was briefly on standby to go into intensive care. As I came through that, I gradually felt I had turned a corner and began to think of life after cancer, away from the constantly beeping chemotherapy drips.

Two PET scans showed that after chemotherapy there was a tiny area of concern, but my treating team were eventually satisfied that I was in clinical remission. I felt a huge sense of relief.

Ironically, just as I finished treatment, I was told my mother was very ill with cancer and had only weeks to live. She lived in Ireland and although going on a plane with a compromised immune system was not ideal, I needed to see her.

I am just so glad I was able to be with her and share the news of my recovery before she passed away. We were very close and I think it gave her great comfort. For me, it was worth the risk.

I have regular examinations. My clinical team are satisfied that my immune system is strong for someone living long-term with HIV, and blood tests and examinations show no sign that the lymphoma has returned, which is great news. In truth, I don't feel like I have recovered my full strength, and get a lot of fatigue, but I am very grateful to be as well as I am today.

I worry about people in a similar situation to me, facing two complicated conditions. Although my doctors were reassuring, I would have found it helpful to read about others who have gone through a similar experience. Hopefully my story will help them realise there is room for hope and optimism and that the internet, while often a help in modern life, can lead you into bleak and dark places that don't always reflect the whole story. That is why it's essential to turn to quality and factual websites like Lymphoma Action.

My husband and I made a decision not to go back to our old lives after my lymphoma treatment. Perhaps not a 'career break', but more a 'cancer break'. We both wanted to adjust our lives to make them less complicated. We were used to living in busy cities with demanding jobs and now yearned for the countryside and a simpler approach – perhaps abroad in France. Who knows?

Wherever I end up, it would be no small satisfaction if I knew that somewhere, somebody reading this and starting the same journey could draw some comfort and reassurance from my experience.

If that is you, I do wish you all the best, for in my case I remain eternally grateful to the health professionals whose help, support and determination to work for the best outcome made such a difference.



Highlights from BSH

This year, the British Society for Haematology held their annual scientific meeting online. Clinical experts presented some of the latest developments across all areas of lymphoma research.

Low-grade non-Hodgkin lymphoma

The **ZUMA-5 trial** studied a CAR T-cell therapy called axicabtagene ciloleucel in 146 people with follicular lymphoma, nodal marginal zone lymphoma or extranodal marginal zone lymphoma who had experienced relapse after at least two previous courses of treatment. Overall, more than 9 in 10 people who took part responded to treatment. Responses were generally long-lasting. Side effects were manageable, with a lower rate of serious side effects than in trials of axicabtagene ciloleucel in people with high-grade non-Hodgkin lymphomas.

The trial suggests that CAR T-cell therapy could be a promising treatment option for relapsed or refractory low-grade non-Hodgkin lymphoma.

High-grade non-Hodgkin lymphoma

The **ZUMA-12 trial** looked at the efficacy of axicabtagene ciloleucel in 32 people with 'high risk' high-grade B-cell lymphoma who had not been treated before. This included people with double-hit and triple-hit lymphoma and large B-cell lymphomas with features suggesting they are likely to be harder-to-treat.

Early results from the trial found that axicabtagene ciloleucel had a high response rate and a manageable side effect profile. The trial is ongoing.

With thanks to Dr Toby Eyre, Haematology Consultant and Honorary Senior Clinical and Lecturer in Haematology, Oxford University Hospitals NHS Foundation Trust, for reviewing this information.

Chronic lymphocytic leukaemia (CLL) or small lymphocytic lymphoma (SLL)

The **BRUIN trial** is studying a drug called pirtobrutinib, a reversible BTK inhibitor in people with relapsed or refractory B-cell non-Hodgkin lymphomas, CLL or SLL. Early results from people with CLL and SLL were presented at the BSH meeting.

Like some other treatments for CLL/SLL, pirtobrutinib blocks a protein called BTK. BTK is part of a pathway that helps B lymphocytes stay alive. Pirtobrutinib binds to BTK in a different way from earlier BTK inhibitors. It targets it more precisely and binds to it more strongly, and unlike earlier BTK inhibitors, the bond is reversible. It is taken as a tablet once a day.

So far, 170 people with relapsed or refractory CLL/SLL have joined the BRUIN trial. On average, these people had had three previous courses of treatment. Most of them had been treated with a different BTK inhibitor before.

The trial found that pirtobrutinib demonstrated promising efficacy in people with relapsed or refractory CLL/SLL. It was effective in people who had had a different BTK inhibitor before. Response to treatment generally improved with continued treatment. Pirtobrutinib was well tolerated.

The trial is ongoing.



T-cell lymphomas

We have previously reported results of the pivotal **ECHELON-2 trial**, which found that brentuximab vedotin combined with CHP chemotherapy was significantly more effective than CHOP chemotherapy in people with previously untreated peripheral T-cell lymphoma.

At the BSH meeting, 5 year follow-up data was presented. This showed that brentuximab vedotin + CHP continued to provide clinically meaningful improvements in outcomes compared with CHOP. In particular, people with anaplastic large cell lymphoma (ALCL) who were treated with the brentuximab vedotin combination had a 34% reduction in the risk of death.

Some people with ALCL who relapsed after their first trial treatment went on to have treatment with brentuximab vedotin on its own. This included people in the brentuximab vedotin + CHP arm and the CHOP arm. Around 6 in every 10 of these people responded to brentuximab vedotin monotherapy, whether or not they had had treatment with brentuximab vedotin before.

Hodgkin lymphoma

A retrospective study of 205 people with advanced Hodgkin lymphoma compared escalated BEACOPP chemotherapy with a modified regimen where the procarbazine component of BEACOPP was swapped for dacarbazine (escalated BEACOPDac).

The study found that modifying the regimen in this way reduced toxicity without reducing efficacy. Escalated BEACOPDac could be a very effective option for advanced Hodgkin lymphoma.

Taking a journey with other people

We are delighted to welcome Emma Claggett, who is our new Live your Life event coordinator. We asked Emma to tell us a bit about herself and explain why our peer-led self-management course is so valuable.



Three facts about me are: I am a keen hockey player, a gym lover and a dog owner. I have 5 years of event experience from running large conferences and award events to small leadership programmes and workshops. I have worked with not-for-profits and corporate companies based in London, and have run events all over the UK and Europe.

If you have just finished treatment or are on active monitoring (watch and wait), the Live your Life programme is designed to help connect you to other people. We know you may feel isolated and find it challenging to adapt to your 'new normal', so we have created a programme led by trained volunteers with a lived experience of lymphoma and supported by clinical nurse specialists.

We want to help you feel empowered and supported in developing coping strategies to adjust to living with and beyond lymphoma and provide you with essential information to help you to lead a positive and healthy lifestyle.

Our workshops are virtual one day events run via zoom and are small groups, up to 20 people, to help encourage discussion and interaction throughout the day. You are welcome to invite someone to join you, whether that's a friend or family member. The workshops are open to anyone living in the UK, aged 16 years or over.

'I found at the end of the workshop that I wasn't scared anymore.'

Lesley, workshop attendee.

The days are based in different regions throughout the UK, allowing us to provide relevant local information. You can also connect with others going through a similar journey who are geographically close by.

'I am a big advocate of the course. It is the best day around for lymphoma patients.'

Charlotte, Clinical Nurse Specialist

Find out more: call **01296 619434** or visit lymphoma-action.org.uk/LYL

A blended approach to services

'Before the pandemic, much of our work depended on meeting face-to-face. COVID-19 had a dramatic impact on this work and led to a transformation which saw us move some of our services, including our Support Group meetings and Live your Life events, online. Delivering these meetings virtually also meant that we could diversify and grow to meet a wider range of needs. We set up specific meetings for young people and for carers; we added new meetings to increase our reach, and in response to findings from our health inequalities research we trialled topic-specific online meetings such as a 'Stem Cell Transplants' meeting.

As we plan for 2022, we are in a position to consider what this support could look like as physical meetings become more viable, although we don't foresee this returning until at least March 2022. We are looking at how we can provide a blended service, allowing us to continue developing online peer support, while also supporting those whose preference has been to meet face-to-face.

We are currently reviewing our processes to see how we can best use our resources and capacity to deliver support for everyone who needs us, while being realistic about the means we have available.

One thing is clear; the challenges of the last 19 months have opened up some exciting possibilities and developments in terms of how we provide support. We hope to engage with our beneficiaries and have more information in the coming months.'

Ropinder Gill, Chief Executive

Lymphoma Action services – here for you

Helpline – call freephone **0808 808 5555** from 10am to 3pm, Monday to Friday for information or emotional support.

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 now have regular online support meetings across the UK as well as meetings for family, friends and carers and for young people (18 to 35). Find out more at 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 about lymphoma, 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



Lymphoma
action 



Dr Dan Monnery



Robbie Fergusson



Giles Andrae



Our most recent podcasts

- Dr Dan Monnery, Palliative Care Consultant, explains what enhanced supportive care is and the benefits of this approach.
- Robbie Fergusson, Scotland Sevens and international rugby union player, talks about lymphoma and being part of Team GB at the Tokyo Olympics.
- Giles Andrae, poet, author, philosopher and illustrator, shares his diagnosis and the extraordinary steps he took to preserve his fertility.

Check out all of our episodes on Spotify and Apple Podcasts, or listen at lymphoma-action.org.uk/LymphomaVoices