

lymphoma matters

ISSUE 119 | SPRING 2021

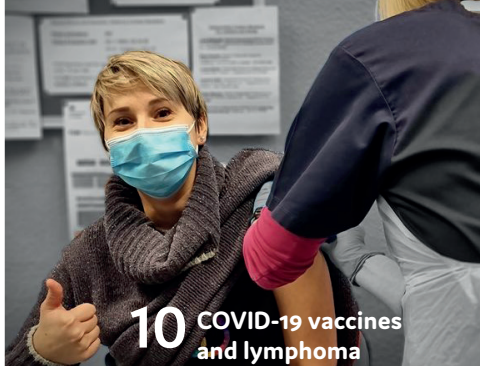
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for 35 years, 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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Editor: Anne Hook

Cover: Sundee and Ricky, who took part in the Lymphoma Action Bridges of Britain (see page 35).

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How you can stay connected

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

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Ropinder Gill
Chief Executive

Even though you might already have had one (or both) doses of vaccine, you might still have some questions. Our article on page 10 covers some of the most common questions.



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

As we look to spring

Welcome to the latest issue of *Lymphoma Matters* which I hope you'll enjoy reading. Together with our supporters, Lymphoma Action has been making a difference to people's lives for 35 years. So, in this, our anniversary year, we're focusing on positive mental wellbeing which reflects everything we do every day to support people affected by lymphoma.

The news surrounding the COVID-19 vaccination programme has certainly lifted spirits, but understandably it has also generated a lot of questions from people living with a blood cancer diagnosis. We have addressed some of these in this issue and will continue to keep you updated on the COVID-19 information pages on our website. As a voice for people affected by lymphoma, we are continuing to put forward the issues that matter to you to the policymakers who are able to address them, whether they are in relation to COVID-19 and blood cancer, or wider questions around developments in cancer treatments and services.

Alongside this we have been creating new and vital resources which you have told us you need, from our information booklet for friends, family and carers, through to our podcast series that focuses on topics of interest for people living with lymphoma.

Lastly, on behalf of everyone at Lymphoma Action, I want to say a huge thank you for your continued support. Thanks to the kind generosity of our supporters, the securing of emergency funds and a generous but unexpected legacy that we received in December, we finished 2020 in a stronger position than we could have hoped for. Over 35 years we have never failed to be amazed by the dedication and support shown to us by you and others affected by lymphoma. 2021 will continue to be a challenging year but we are positive about what we can achieve with your help.

Ropinder Gill
Chief Executive



Important reminders about COVID-19

After having the COVID-19 vaccine, it is important to carry on taking appropriate measures to reduce your risk of infection. If shielding measures are recommended where you live, you are advised to continue shielding even after you've been vaccinated.

If you have symptoms of lymphoma or signs of infection, please contact your GP surgery or your clinical team. It is important that you don't ignore symptoms that could be serious.

We continue to update our website regularly with the latest news on COVID-19 at [lymphoma-action.org.uk/COVID19](https://www.lymphoma-action.org.uk/COVID19)

Blood Cancer Alliance report on access to new drugs and treatments

When it comes to treatment, blood cancers like lymphoma are more complex than solid tumours.

Surgery and radiotherapy are rarely an option.

As a result, ensuring that people with blood cancer have timely access to the best and most effective new medicines and treatment is critical to improving outcomes.



The future of blood cancer treatment is promising, with many new treatment options on the horizon.

The Blood Cancer Alliance, of which Lymphoma Action is a member, have published a report that identifies challenges in accessing new drugs and treatments for people with blood cancer on the NHS. This new report shows that:

- Two in every three blood cancer patients (67%) are concerned about accessing new and effective treatments, with one in ten (11.5%) stating they are extremely concerned.
- Whilst there are many new blood cancer treatments coming down the pipeline, NICE and the SMC (the bodies that recommend whether or not new treatments should be available on the NHS) need to be better prepared and equipped for their appraisal.
- There is an urgent need for patients to be more involved in research and development. The Alliance is calling on NICE to improve its use of patient perspectives as part of its decision-making process.

Read the report at bit.ly/3jiXAdW

Global patient survey on lymphoma and CLL

The Lymphoma Coalition, of which Lymphoma Action is a member, has published the results of its 2020 Global Patient Survey. The survey is produced every 2 years, and aims to understand patient experiences of lymphomas, as well as the impact of treatment and care worldwide. The Lymphoma Coalition and its global members use the results to ensure patient voices are heard and to drive planning, actions and support.

Lymphoma Action supported and promoted the survey. In the UK, 679 people responded to the patient survey and 64 to the caregiver survey.

Summary of key points from the UK survey

- Just over half the people who responded (53%) said that they needed more information about diagnosis and what it means, 46% needed more information about treatment options and 43% wanted more information on the side effects of treatment.
- The five most reported side effects of treatment were fatigue (79%), hair loss (56%), nausea and vomiting (49%), peripheral neuropathy (49%) and constipation (46%).
- The most reported psychosocial effects that patients experienced in the last 12 months as a result of their diagnosis were fear of progression of their lymphoma (44%), fear of cancer relapse (40%), anxiety (35%), depression (30%) and change in physical appearance (28%). Most people (83%) said that they felt there were no barriers to them receiving treatment.

The Caregivers' survey highlighted the extensive range of support caregivers provided, and that providing emotional support was the hardest part of caregiving.

You can read the full report at bit.ly/3tpShhl

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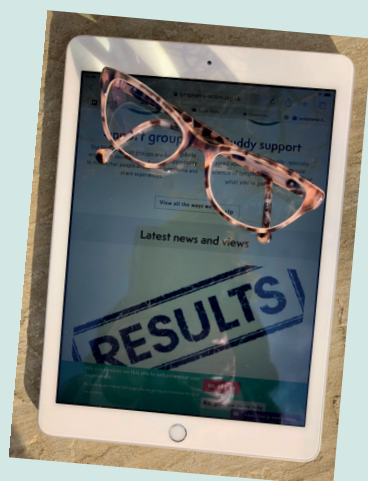


Opportunity to get involved if you were treated for Hodgkin lymphoma between 1 and 5 years ago

Research participants are needed for a study of treatment decisions in Hodgkin lymphoma.

If you have been treated for Hodgkin lymphoma between 1 and 5 years ago, the Nuffield Department of Population Health at the University of Oxford would value your help.

The information from this study will inform the design of a decision tool to help people treated for Hodgkin lymphoma in the future. If you'd like to find out more contact Dr Rebecca Shakir at rebecca.shakir@ndph.ox.ac.uk



Lymphoma Voices

Why not give our podcasts a listen as they offer lively conversation around lymphoma topics? We are regularly recording more in the series, so check out:

lymphoma-action.org.uk/LymphomaVoices

Currently available:

- Presenter and broadcaster Emma Forbes talks about supporting her sister after a diagnosis of lymphoma.
- Sisters Sarah Standing and Emma Forbes share a very personal conversation about how they are supporting each other during Sarah's diagnosis and treatment.
- Consultant Counselling Psychologist Angela Waind shares her thoughts about emotional wellbeing and mental health.
- Consultant Haematologist Dr Graham Collins gives an overview of lymphoma and explains why he finds it so interesting.
- GP Dr Sarah Jarvis, who you may know from the Jeremy Vine Radio 2 show, talks about the role of the GP in managing lymphoma.



New book for family, friends and carers now available

Our new book entitled *When someone close to you has lymphoma* is now available.

It aims to help you take care of yourself and the person with lymphoma. It contains practical tips and ideas to help with emotional support, as well as quotes from others who have experience of caring for someone who has lymphoma.

Download a copy at lymphoma-action.org.uk/Books

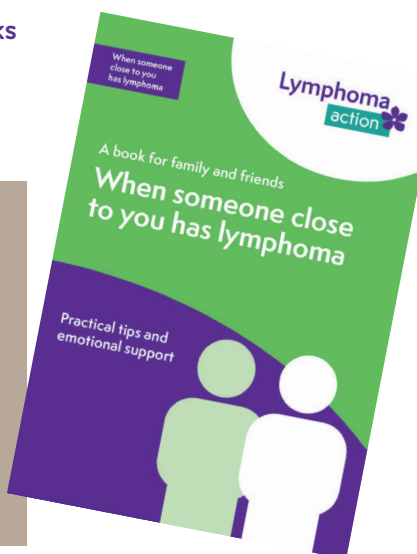
or order a copy free of charge at

www.lymphoma-action.org.uk/Shop



When someone close to you has lymphoma, it can feel like you've both been diagnosed. Remember - they're still the same person & it doesn't define them. Most importantly, offer support. This book has practical tips to help you and the person you care for.

Lucy, whose husband was diagnosed with lymphoma





Trust your instincts

Nichola talks to us about caring for her son Jo

I have three children. Jo is 16, Ella is 15 and Tobey is 12. I work full time as a Veterinary Practice Manager, and was previously a veterinary nurse, so I have a medical background – although, granted, in animals!

In October 2018 Jo went on a school trip to Germany. I missed him terribly the 5 days he was away; it was actually the first time he'd been away from us all. When he came back, I noticed he had a terrible itch. I thought it must be some sort of allergic reaction, so we made adjustments. We changed to baby washing powder, simple shower soaps and shampoos in the hope it would improve the itch. It didn't!

We went to the GP several times who continued to think it could be dermatitis, eczema or dry skin, but none of the creams made any difference. At this point Jo had no visible skin issues apart from the marks he was making to himself by scratching. As a family we were even treated for scabies!

On the evening of 30 June 2019, Jo noticed a lump in his neck and ran downstairs to ask me if I thought it was normal. I instantly knew something wasn't right and, with the continued itching, started to think this could be lymphoma.

I got Jo in to see the doctor the very next day. The GP thought the lump was enlarged lymph nodes

due to an infection, but Jo had not been poorly at all. Blood was taken there and then; Jo's white blood cells were slightly increased which coincided with the doctor's original thought of an infection. Jo was prescribed antibiotics and steroids for the itching and was advised he'd need an ultrasound scan if the lumps didn't go down.

The antibiotics made no difference and Jo developed the worst rash I have ever seen about a week after the antibiotics had finished. We were seen out of hours at the hospital by a nurse who said it looked like an antibiotic reaction but she would be keen to see what happened going forward, as it was nothing she had seen before. The rash took 10 days to improve.

On the 28 July Jo went for an ultrasound. In a message to my friends I said 'Doc not worried – recheck 2 months'. This was the point I thought I was probably over-reacting. Doctors thought everything was OK, my family thought everything would be OK and my work colleagues thought everything was OK. I had a word with myself and told myself to calm down!

The itching had got so bad that Jo couldn't sleep and was covered in scratches. He was prescribed strong antihistamines but they had no impact and he'd had enough. It was definitely affecting his mental health: from a happy boy, he was now quite often in tears. I called the doctor to share my worry that it could be lymphoma. He referred Jo to haematology to rule out lymphoma. In the meantime, he prescribed more steroids.

On the 16 September Jo had a repeat ultrasound. As there was no change in the lump, the sonographer recommended a biopsy and just over a week later we had a haematology appointment. I asked my husband to come along; he knew I was worried. The biopsy, taken 9 days before, revealed that Jo had Hodgkin lymphoma - blood cancer. My worst fears were confirmed.

Although I'm glad I kept pushing to get an answer to the itching, I really wish I had pushed harder, especially as I think of how much Jo has suffered with the itching. It really did cause unnecessary suffering.

The haematology team explained that as Jo was only 16 he would be best referred to the Teenage and Young Adult Ward, which turned out to be the best advice ever.

The first appointment covered scans, blood tests and fertility and from then on everything moved on really quickly!

Jo was offered the choice of two chemotherapies:

- the standard treatment of six cycles of ABVD chemotherapy and possible radiotherapy afterwards; or
- a clinical trial of a more intensive chemotherapy regimen given over 4 months but with a lower likelihood of needing radiotherapy.

Our medical team gave us all the details about the clinical trial but the choice was for Jo to make. We went home with leaflets and had 48 hours to decide. It was a difficult decision, and you hope you are making the right one.

We weighed up the pros and cons of the trial versus standard treatment, but what swayed the decision for Jo was the hope that by being involved in a clinical trial, he may be able to help others in the future. He's an amazingly caring boy and I was so proud that he thought in this way.



Jo, having his treatment

Treatment began 26 October. On day 15 Jo began to lose his hair **which was a really big thing!** For him, losing his gorgeous long curls felt like losing his identity. For us, it made the cancer seem visible. His best friends arranged a facetime call and said they would shave their hair off to support him.

After two cycles of treatment with a chemo regimen called OPEA, Jo had a scan. It was clear - the cancer had gone!

Jon then went on to the next phase of treatment: two cycles of a chemotherapy regimen called DECOPDAC-21. The clear scan gave Jo the lift he needed to get through and we pencilled in the date that treatment would hopefully end, providing his blood counts remained stable.

The trial went really well. Jo coped amazingly with very few side effects. The care at the Teenage and Young Adult Ward has been fantastic. We have made friends for life with parents and other young people going through similar treatments to Jo.

Now treatment is complete I am already starting to forget the worst parts, but there have been really difficult days. Jo felt edgy in the beginning (due to the steroids) and Tobey got the brunt of it. It has been utterly exhausting and I have worried **all** the time; I still do now. I'll be honest I have not coped very well at all.

I actually feel like a different person. It's a good job my husband Glenn has held it together; I think he coped by keeping fit. My release would have been meeting up with girlfriends and talking things through. They have all been there at the end of the phone but COVID has put a different spin on things for sure. Nothing in comparison to Jo of course. We thought it was bad that he missed out on his last days of school, his prom and his GCSEs due to COVID; never did we expect cancer to be part of the mix.

I had heard the saying: 'It is during the worst times of your life that you will get to see the true colours of the people who say they care for you.' We have certainly seen that. Our support network is bigger than we ever imagined; it is utterly heart warming! Some days the little texts or virtual hugs actually got us through the day. We will never forget that!

On 20 January 2021, Jo had his last treatment and rang the bell at the Teenage and Young Adult ward surrounded by his specialist team.

We can breathe again!

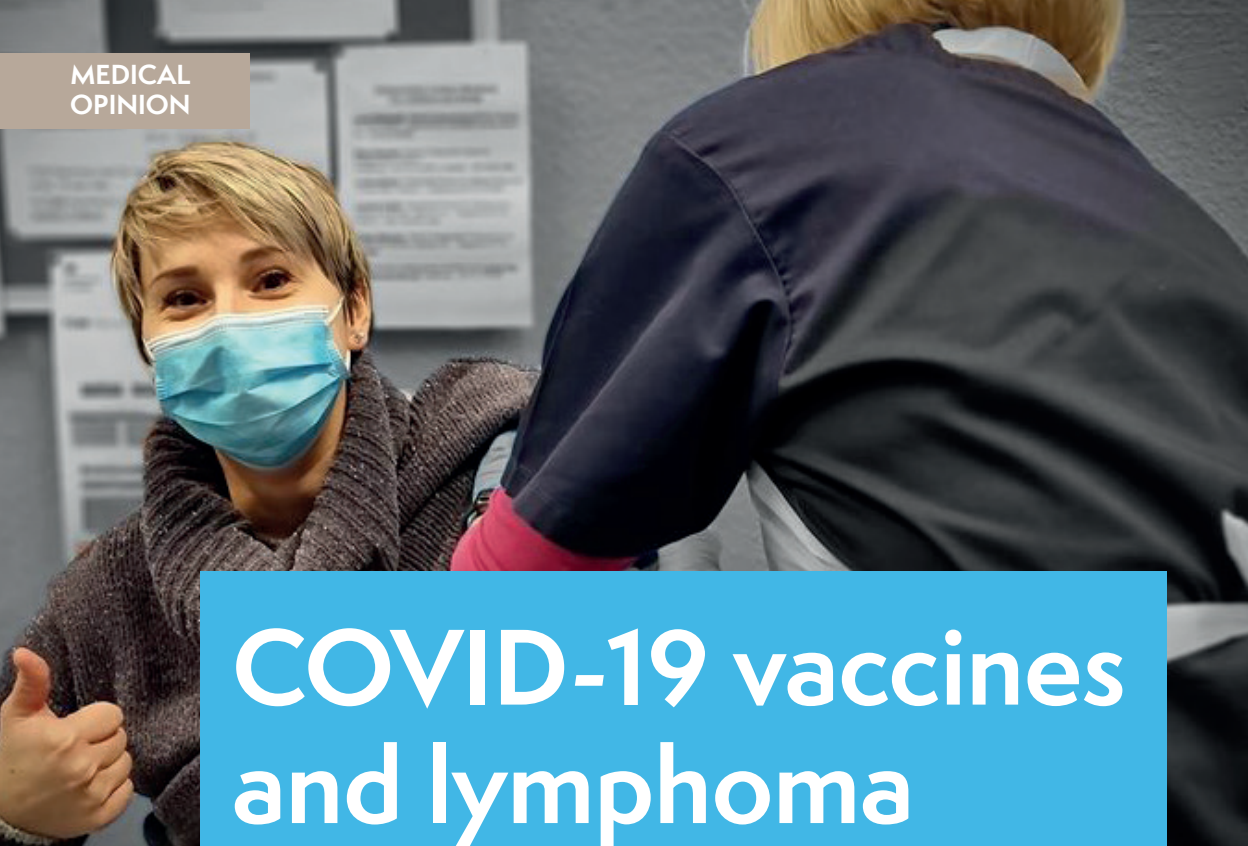
For now I will continue to work from home, at least until Jo has had his COVID vaccination. Ella and Tobey will carry on with home schooling (that I was delighted about to keep Jo safe) and Glenn will continue to follow super-strict social distancing at work, so we can keep safe as a family. Jo will continue to visit the hospital for blood tests and checks.

I will continue to raise awareness of lymphoma and try and help other parents out there.

My take-home message from this experience is always trust your instincts!

Lymphoma Action have produced a new book, *When someone close to you has lymphoma*, to help you manage the physical, practical and emotional aspects of caring for someone with lymphoma. We also have a *Young person's guide to lymphoma*. Download a copy at lymphoma-action.org.uk/Books or order a free copy at lymphoma-action.org.uk/Shop





COVID-19 vaccines and lymphoma

By the time this edition of *Lymphoma Matters* lands on your doormat, many of you will have been invited for your first dose of coronavirus vaccine. Even though you might already have had one (or both) doses you might still have some questions about the vaccines. This article covers some of the most common questions. Information correct as of 10 February 2021.

How do the vaccines work?

The vaccines work by training your immune system to recognise and respond to a protein that's found on the surface of the coronavirus. The different vaccines do this in slightly different ways.

- The Pfizer/BioNTech and Moderna vaccines are 'mRNA' vaccines. In essence, an mRNA vaccine is a set of instructions for making a protein, packaged inside a fat droplet. The instructions are called messenger RNA (mRNA). When it gets into your body, the mRNA in the vaccine tells your own cells to make the protein. Once your cells have made the protein, they break down the mRNA and get rid of it.
- The Oxford/AstraZeneca vaccine uses what's called a 'viral vector' to deliver instructions to your cells. A viral vector is a harmless virus (not the coronavirus) that has been modified in a lab so it contains the genetic code for a coronavirus protein. Once it gets into your body, the viral vector enters your cells and uses your cells' own machinery to turn its genetic code into mRNA. The genetic code does not become part of your DNA. The mRNA tells your cells to make proteins, including the coronavirus protein. These proteins then stimulate your immune system.

The Oxford/AstraZeneca vaccine is based on a virus that causes the common cold in chimpanzees. It doesn't infect humans. The virus has also been modified to make sure it can't make copies of itself. This means it can't cause infections. It also means it can't mutate to become infectious, because mutations only happen when viruses are reproducing.



The particular protein the coronavirus vaccines tell your cells to make is called the 'spike protein'. It's the protein the coronavirus uses to get inside your cells and cause an infection. However, the protein on its own is harmless.

Your immune system recognises that the new protein isn't usually found in your body, and responds to it by making antibodies. It also makes immune memory cells that remember the protein. This means your body can respond very quickly if it comes across the protein again. If you're exposed to the virus in the future, your body knows how to fight it off and has its attack forces ready.

How were vaccines developed so quickly?

Developing new vaccines or medicines usually takes many years. The coronavirus vaccines went through all the usual trials and processes but the timescale were cut dramatically without cutting corners. Lots of factors contributed to this.

- The vaccines were developed using existing techniques and technologies. Scientific institutions across the world collaborated and shared their research to help this process.
- Getting funding for research usually takes a long time. Developing a coronavirus vaccine was urgent, so governments and companies provided funding very quickly.
- Because research into coronavirus vaccines was a priority, it could 'jump the queue' at,

for example, laboratories and manufacturing facilities. Other research projects were put on hold, to allow staff to focus on the vaccine programme.

- Recruiting enough volunteers for clinical trials can often take months or even years. However, hundreds of thousands of people signed up to take part in the vaccine trials as soon as they were able to.
- Vaccine developers submitted clinical trial data to regulatory bodies as soon as it was available, rather than waiting to submit all the data at the end of the trials. This speeded up the approval process.
- Vaccine manufacturing companies scaled up production before the vaccines were approved – a financial risk that companies would not ordinarily take. This helped make sure there were millions of doses available as soon as the vaccines were approved.

How do we know the vaccines are effective?

All the vaccines have been tested in very large clinical trials involving tens of thousands of people. People who took part in the trials were randomly allocated to have either the coronavirus vaccine or a control vaccine (a dummy vaccine or the meningitis vaccine, depending on the particular trial).

After having the coronavirus or control vaccine, people carried on with their normal lives, following the local social distancing guidance. They were not deliberately exposed to coronavirus infection.

The researchers compared how many people developed COVID-19 in each group. The number of people who developed COVID-19 was much lower in people who had the coronavirus vaccines than in people who had the control vaccines. This shows that the vaccines are effective. They were particularly effective at preventing severe illness due to COVID-19. The trials also looked at side effects in the different groups. The risk of serious side effects was extremely low and there were no major safety concerns.

What are the main side effects of the vaccines?

The main side effects of the vaccines are pain and redness where the injection goes in and mild flu-like symptoms. These typically last a day or so. Some people develop swollen lymph nodes, which generally go down within around 2 weeks.

Now that the vaccines are being offered to millions of people, they are being monitored through the 'yellow card' scheme to make sure there are no unexpected issues. Anybody who thinks they've experienced a side effect after having the vaccine can report it at coronavirus-yellowcard.mhra.gov.uk

Do the vaccines protect people who have lowered immunity?

Researchers are looking at how effective the vaccines are in people with lowered immunity but the data isn't available yet. Based on the way the vaccines work, and on other vaccines in common use, people with low immunity are likely to have a lower response to vaccination than other people. However, the vaccines are still likely to offer some degree of protection. This means that they are likely to reduce the risk of developing COVID-19, and people who do develop it are likely to experience a less severe illness.

How do I know if I've responded to the vaccine?

Individual immune responses to the vaccine are not routinely assessed.

No vaccines are 100% effective in all people. There is a chance that you might still develop COVID-19 even if you've been vaccinated, but the risk is lower and the illness is likely to be less severe. It's important to keep following social distancing guidelines.

The vaccines reduce the risk of developing COVID-19, and people who do develop it are likely to experience a less severe illness.

Which vaccine is better for people with lymphoma?

The vaccines have not been compared with each other in clinical trials. The trials all used slightly different criteria to measure how effective the vaccines are, so it's not possible to compare the results fairly. Based on the way they work, there is nothing to suggest that any one is more suitable than any other for people with lymphoma.

There are no particular safety concerns about using any of the vaccines in people with lymphoma. None of the vaccines are able to cause infections so they can all be given to people who have lowered immune systems. The current advice is that all of the approved vaccines are suitable for people with lymphoma and there is no preference for any particular one.

Research on using the vaccines in people with lowered immunity is ongoing. If there is any evidence in the future that a particular vaccine might be better in these people, the advice could change.

Why do I need a second dose?

It is important to attend for your second dose when you are called for it.

The coronavirus vaccines that are approved for use in the UK usually produce an immune response within 2 to 3 weeks of having the first dose. Having a second dose strengthens this response and boosts your immune memory.

Will I need regular boosters?

Scientists don't know yet how long the protection from the vaccines lasts. The people who took part in the clinical trials are being followed-up long-term to find this out. If the immune response to the vaccine wanes over time, it might be necessary to have regular booster doses.

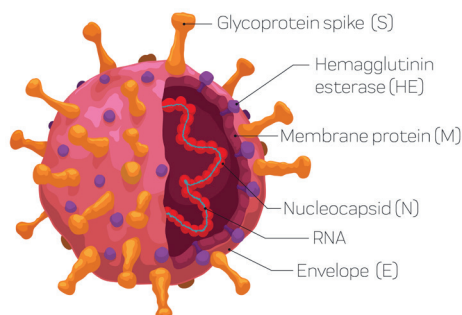
Why do I still have to follow the government guidelines?

Having the vaccine reduces your risk of becoming seriously ill with COVID-19, but it's not clear yet whether it stops you picking up the virus and spreading it to other people. This is why it's important to keep following the government guidelines, especially when the rate of coronavirus infections is high. If you have been recommended to shield, you should carry on shielding even if you've been vaccinated.

Will the vaccines work against different variants of coronavirus?

Viruses mutate all the time. Most mutations don't affect the way the virus behaves, but sometimes they affect proteins or pathways that change how the virus infects people.

Some variants of the coronavirus might have mutations that affect the spike protein – the part of the virus that the vaccines train your immune system to recognise.



CORONAVIRUS STRUCTURE

However, the coronavirus spike protein is very large and your immune system reacts to lots of different parts of it. Mutations are unlikely to affect **all** the parts of the protein that your immune system responds to. This means that the vaccines are still likely to offer some level of protection against variants with mutated spike proteins, although they might be less effective than they were against the original strain.

However, because of the way the vaccines have been developed, it's a fairly straightforward process to 'tweak' the mRNA or the viral vector so it codes for the variant spike protein. This is a much quicker process than developing the vaccine in the first place. It's similar to the changes that are made to the flu vaccine every year to make sure it protects against the predominant strain.

It's important to keep following the government guidelines, especially when the rate of coronavirus infections is high.

With thanks to our Senior Medical Writer Dr Vicki Gregory for writing this article and Dr Wendy Osborne, Consultant Haematologist, Freeman Hospital for reviewing it.

Information correct at time of print (10 February 2021). For more information visit lymphoma-action.org.uk/COVID19

Fundraise with us!

In 2021 Lymphoma Action celebrates its 35 year anniversary and we are pleased to invite you to join in with the celebrations!

March: Lymphoma Action's Marvellous Makeathon!



Unleash your creativity this spring by joining in our Marvellous Makeathon!

The idea is simple - have fun creating something special (it could be a painting, a poem, a pie, or anything you like) and make a small donation to enter what you have created into our competition before the closing date on April 18. You can enter as many different creations as you like, so there is no limit on how much fun you and your family can have! Each entry will be in with the chance of winning a spring hamper full of delicious treats.

Full details are on our website at lymphoma-action.org.uk/marvellous-makeathon

April: Lymphoma Action Gaming Challenge

Ready player one? We are challenging you to use your gaming skills to help support people affected by lymphoma!

It's up to you to pick your own challenge - it could be to play solo for a certain number of hours in a row, or organise a relay event or tournament with friends. Alternatively (we think this idea might be a popular one with parents!) you could give up gaming for a certain number of days or weeks.

See our website for how to take part lymphoma-action.org.uk/gaming-challenge



May: Make Every Mile Count Cycling Challenge



Take your seat: join Team Lymphoma for our virtual cycling challenge this May!

We would love you to join us and help celebrate our 35 year anniversary by cycling 35 miles over a weekend in May. You can choose whichever weekend suits you and either cycle 35 miles in one day, or split the distance over two days.

Register on our website lymphoma-action.org.uk/make-every-mile-count

June: SAVE THE DATE - Anniversary Tea Party

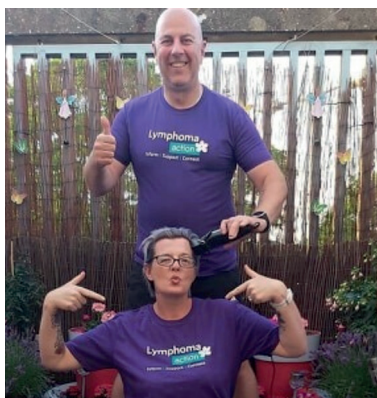
Fancy a cuppa? Our Anniversary Tea Party will take place on June 19 and 20. We would love you to be part of our celebrations!

It's a great excuse to bring friends and family together (in person or online) for teas and coffees, refreshing soft drinks, or maybe even some fizz - whatever is your cup of tea! And every penny you raise will help us make sure no one has to face lymphoma alone.

Full details our website lymphoma-action.org.uk/anniversary-tea-party



A close shave: brave the shave for us!



Over the last few months, lots of us have been really missing being able to visit our hairdressers for a trim. So if you have ever considered doing a sponsored shave or haircut to raise money for people affected by lymphoma, now is the perfect time! We have lots of resources on our website to help make your head shave or haircut a success. Have a look at our tips for braving the shave at lymphoma-action.org.uk/sponsored-shaves



Celebrating 35 years of making a difference

Our founder's daughter explains why Lymphoma Action is still close to her heart as the charity celebrates 35 years of supporting people affected by lymphoma.

Anna explains how her parents, Tim and Felicity Hilder, were instrumental in starting the charity over 35 years ago.

'My father was diagnosed with non-Hodgkin lymphoma (NHL) in 1972 at the age of 42. Under the care of Dr Tony Jelliffe at Mount Vernon Hospital, he was treated for 6 years with chemotherapy and radiotherapy and carried on taking chlorambucil for a further 4 years.

Dad was frustrated that there was so little information about NHL, or support available to help patients cope with the disease. However, he had such a positive attitude to his illness that the ward sister often asked him to talk with other patients. Dr Jelliffe heard about this and put dad in touch with two of his other patients, Lewis Cash and Richard Franklin. They both had Hodgkin lymphoma, and a similar desire to make a change; together they formed a small support group.

At the time dad was working in London and it wasn't until he retired in 1985 that he had time to devote himself to taking forward the ideas that he, Lewis and Richard had.



Tim and Felicity

In 1986 the Hodgkin's Disease Association (HDA) was born. There was a steering group of five people - Lewis and Jackie Cash, a young Hodgkin lymphoma patient called George Ball and my parents. They had a treasurer and dad's consultant Dr Tony Jelliffe was the President. In addition, Dr Gillian Vaughan Hudson became their medical advisor.

They worked out what the purpose of the Association would be: giving information and support to people with lymphoma. They created two small booklets, which they wanted to be easy to understand, and provide general advice and support. An answerphone was bought to take calls, which was manned in the evening from 7-10pm in my parents' house.

My brothers and I remember dad leaving the dinner table on many occasions to answer a call; for him the person in need was more important. To spread the workload, and ensure that patients could contact someone, they involved a range of local volunteers to whom the answerphone was diverted on a rota basis. It was a small and friendly team, some with a medical background, but all just wanting to help.

Dad had a passion for life and was a real 'people person'. I remember one reporter commenting 'If talking was an Olympic sport, Tim Hilder would win gold!' With his enthusiasm and attention to detail, and mum's constant support, the charity grew steadily over the years.

Dad died in 1994 and mum carried on as a trustee, very much still involved in the charity until her death in 2015.

My parents would always go the extra mile and I get the distinct feeling that the staff there still do. The fundamentals of what my parents started are still very evident – the information, the helpline, the newsletter which is now a magazine, but still offers the same support and information to people.

My brothers and I are incredibly proud of what our parents achieved – from the start they put their heart and soul into developing the charity, and devoted all their efforts to further its goals. This was recognised in 2012 when mum was honoured to receive an OBE, which she accepted on behalf of dad and herself.

I know mum was especially proud of the charity's funding of the lymphoma clinical nurse specialists. This was a post introduced by Lymphoma Action, which has been rolled out through haematology departments nationwide and has made such a difference to the care of people with lymphoma.



Anna, Colin and family join Bridges of London

Although I'm not actively involved in the running of the charity, it is still very close to my heart. For our 35th wedding anniversary in 2019, my husband Colin and I asked friends and family to join us at the Bridges of London fundraising event for Lymphoma Action. It was a glorious and joyful day, made even more special because of our close tie to the charity.

I really enjoy hearing about how the charity is developing. My parents wanted to support people affected by lymphoma and it is with pride that I watch the charity offer more and more ways of doing this.'



Felicity receives her OBE in 2012

Describing lymphoma

Our 'Ask the expert' this edition is with Dr Graham Collins, Consultant Haematologist and NIHR BRC Senior Research Fellow, Oxford University Hospitals NHS Foundation Trust.

People often find it challenging to describe lymphoma to family, friends or colleagues. Is there a straightforward way to describe lymphoma?

If you have lung cancer, breast cancer or prostate cancer, it is fairly obvious what you have. But with lymphoma, many people do not understand which part of the body is affected and without the word 'cancer' it isn't clear that it is a cancer.

Lymphoma is a cancer of the immune system and specifically the adaptive immune system. The adaptive immune system has memory, so if you have a viral infection or vaccine, it can remember it and attack that bacteria or virus the next time around.

The adaptive immune system is made up of lymphocytes (a type of white blood cell) and it is when those lymphocytes are dividing out of control that cancer develops.



Lymphocytes travel around the body, but are mainly found in lymph glands (which are part of the lymphatic, or drainage system, of the body) and the spleen. They are constantly surveying, ready to respond to any danger in your body.

I would call lymphoma a cancer of the immune system. Many people regard lymphoma as a blood cancer, as lymphocytes can be found in the blood. However, blood tests are often normal in lymphoma.

Do you know what causes lymphoma?

There is a lot of research underway, but for most people we cannot identify a cause. In most cases, it doesn't seem to be hereditary and it does not seem to be environmental. There are some types of lymphoma, however, where a link can be recognised:

- In South East Asia, T cell lymphomas are more common than they are in Western Europe, Australia or North America, suggesting a geographical link. In fact, this is at least partly explained by some types of virus being more common in that part of the world.
- A type of lymphoma of the stomach called gastric MALT lymphoma is caused by an infection of the stomach called H. pylori. However, gastric MALT lymphoma is a rare, while H. pylori is a common infection, so there are clearly other factors at play.
- We know that suppression of the immune system, for example if you have had a kidney transplant and you are on immunosuppressant drugs, can increase your chance of developing lymphoma.

Most cancers are more common in people as they get older. This is true for non-Hodgkin lymphoma, but Hodgkin lymphoma is the most common cancer in teenagers and young adults. So far, scientists don't know why this is.

How many types of lymphoma are there?

We know of over 50 different types of lymphoma, but more subtypes are being identified all the time. In broad terms they are split between Hodgkin and non-Hodgkin lymphoma.

Hodgkin lymphoma is defined by an abnormal cell called the Reed Sternberg cell, which pathologists can identify under a microscope. 90-95% of Hodgkin lymphomas

are classical Hodgkin lymphoma, with 5-10% being a rare subtype called nodular lymphocyte-predominant Hodgkin lymphoma.

Non-Hodgkin lymphoma (NHL) is more complicated. It is divided between B-cell or T-cell type, depending on the lymphocytes that are affected (lymphocytes can either be B-cell or T-cell). B-cell NHL is far more common than T-cell. Non-Hodgkin lymphoma is further divided into high-grade or aggressive, or low-grade and indolent.

Within each of those categories, there are distinct sub-types. The most common high-grade non-Hodgkin lymphoma is called diffuse large B-cell lymphoma, and the most common low-grade is follicular lymphoma.

High-grade and low-grade non-Hodgkin lymphomas behave very differently. People with a high-grade lymphoma can be very unwell because the lymphoma is growing quite quickly. This may sound worrying, but the good news is that with the right treatment most people will be cured, usually with chemotherapy in combination with an antibody therapy.

With low-grade non-Hodgkin lymphoma, people are usually well and may only have sought medical help because they have noticed a lump or had an abnormal blood test. If they are not experiencing troublesome symptoms, their medical team will probably suggest a period of active monitoring or 'watch and wait', rather than treatment. Although these low-grade lymphomas are generally not considered curable, when treatment is needed, it is usually very good at getting people into remission. Those remissions can last many years so the prognosis, in most cases, is very good.

Why is low-grade non-Hodgkin lymphoma generally not curable when the high-grade and Hodgkin lymphomas are curable?

Most treatments for lymphoma, such as chemotherapy, work better on cells that are rapidly dividing. In low-grade non-Hodgkin lymphoma the cancer cells are growing far more slowly, so while treatment is good at reducing the bulk of the lymphoma, theoretically there may still be cells that hide away from treatment.

Many lymphomas have very complicated names. Can you explain how lymphomas are given their names?

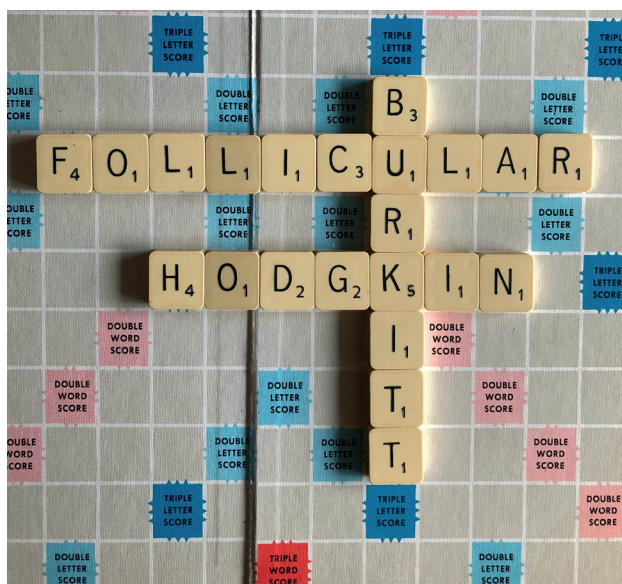
A lot of the names are to do with what the lymphoma looks like down the microscope. Lymphoma is diagnosed by a pathologist from a biopsy and the lymph node has a very specific structure. The pathologist can identify whether the lymphoma is a B cell or T cell type using special stains.

If we take diffuse large B-cell lymphoma (DLBCL) as an example, the normal lymph node architecture is replaced by sheets of abnormal cell in an unstructured (or diffuse) way. The cells are larger than normal lymphocytes and special stains show they are B-cell. Hence diffuse large B-cell lymphoma.

The name follicular lymphoma was given because the normal lymph node structure consists of round structures called follicles (the word means 'little bag'). But with follicular lymphoma the follicles are very big, expanded and crowded together.

Some are named after the person who identified them. For example, Hodgkin lymphoma is named after the 19th century pathologist Thomas Hodgkin (a medical hero of mine), who first described the cases of lymphoma that took his name. His original specimens can be found today in St Thomas' pathology museum!

Burkitt lymphoma is named after Dennis Burkitt, an Irish surgeon who did a lot of work in sub-Saharan Africa in the 1960s and described children who had lymphomas of the jaw and the face.



Waldenström's macroglobulinaemia is an example of the lymphoma being named after the person who recognised it as well as the biology of the disease. The Swedish doctor, Jan Waldenström, described people who had very thick blood. He realised the blood was thick because of large abnormal plasma proteins found in the blood called macroglobulins.

Is a specific diagnosis critical for deciding treatment?

Absolutely, because treatment depends on the sub-type you have. This is why sometimes a repeat biopsy is needed. For example, a fine needle aspirate which, as the name suggests, sucks out cells with a fine needle, may only be able to confirm 'lymphoma' or 'no lymphoma'. A second biopsy, a core biopsy, is then needed, where a small piece of the lymph node is removed intact, and used to sub-type it. Sometimes, a small operation is needed to remove a whole abnormal lymph node.

People with lymphoma are often only diagnosed at an advanced stage.

Why is this?

With many cancers, it is important that the cancer does not spread around the body. However, with lymphoma, lymphocytes

travel around the body as part of their normal job. This is why people are often diagnosed at an advanced stage, and also why it can be more difficult to diagnose. While this can sound very scary, treatment can still be very effective. With Hodgkin lymphoma and high-grade non-Hodgkin lymphoma we can still cure in most cases, and we can manage low-grade non-Hodgkin lymphomas well.

However, I would emphasise that it is important that if someone has symptoms they seek medical attention immediately.

To hear Dr Graham Collins' podcast on why he finds lymphoma so interesting visit lymphoma-action.org.uk/LymphomaVoices or share.transistor.fm/s/4b7148co. In the podcast he also discusses the different treatments and outcomes for lymphoma.

Virtual London Marathon: your run, your way

Become part of our 2021 London Marathon team and take part in the 2021 virtual London Marathon which takes place on Sunday 3 October 2021.

To celebrate our 35 year anniversary year we have secured 35 places in the 2021 virtual London Marathon and would love for you to be part of Team Lymphoma! You don't have to be super fit or super fast, you have 24 hours to run/walk your 26.2 miles. The official London Marathon app will enable you to log your 26.2 miles and earn your coveted medal and New Balance finisher t-shirt.

For one of these guaranteed places we ask for a registration fee of £35 and your sponsorship target is £350. **Early bird offer:** if you register for a place before the 31 March 2021 the registration fee is £20. We would also supply you with one of our running vests. Contact fundraising@lymphoma-action.org.uk or call 01296 619419.



Mark, who ran for us in 2020



Katie's story

Katie talks about people's reaction to her Waldenström's macroglobulinaemia diagnosis and shares her experience of a clinical trial

In 2010 I was diagnosed with breast cancer. I had so many cards and calls wishing me well with my treatment, my home looked like a florist.

More recently I had a hysterectomy, and my female friends, family and colleagues gave me lots of support. But people don't seem to know how to react to my diagnosis of Waldenström's macroglobulinaemia. I wonder why that is? Is it because it is such a complicated disease to understand? Is it because I wasn't going to receive treatment straight away, so people didn't understand how serious this was?

Was it because I looked no different? The reality for me was that I considered this to be really serious.

My lymphoma story really began after my hysterectomy in 2019. The operation went smoothly, and I was recovering well. After the operation, I had to inject myself with heparin, a blood thinning drug, to avoid blood clots. I noticed a strange patch of skin which turned very dark. I happened to have a nurse friend visiting and shared my concerns and showed her what I was talking about. She said she'd never seen anything like it before and urged me to go to my GP.

The GP referred me to a dermatologist who initially thought this strange skin colouring was due to an allergic reaction, possibly to the heparin. However, several tests were organised to look into this and, through a process of elimination, I was eventually diagnosed with blood cancer summer 2019.

I was diagnosed with Waldenström's macroglobulinaemia (WM) and was put on active monitoring, or 'watch and wait', with a review planned every 3 months. I thought this would last for months and hopefully years, but unfortunately it became

evident fairly quickly that I would need to start treatment.

My consultant spoke to me about a clinical trial called the RAINBOW trial for people who hadn't had any prior treatment. RAINBOW is a phase 2/3 trial comparing ibrutinib plus rituximab with the standard treatment of dexamethasone, rituximab and cyclophosphamide.

It was at this point that lockdown happened and the trial was suspended. I had a decision to make on whether to start standard treatment or to wait for the trial to restart. My doctor felt it was safe for me to hold back treatment for the time being and even though I thought the trial may not happen, I was keen to wait and see.



As someone currently undergoing treatment as part of a clinical trial, I would recommend to anybody to consider it as an option if it is a possibility for you.

In October I was notified that the trial had restarted. I had several discussions with my clinical team and was given all the details about the clinical trial. Although the information looked daunting, I am used to technical information in my job so I didn't find it intimidating or scary. However, I can imagine for many people the paperwork around clinical trials might seem that way. My thoughts were that I would get more monitoring and it felt like something important to do to move treatment forward.

The trial was randomised so I couldn't choose which treatment I had and neither could my doctor. I knew the options were

the chemotherapy I would have had as a matter of course or a new immunotherapy drug (ibrutinib plus rituximab). I was actually quite pleased when I heard I had been placed on the immunotherapy arm of the trial and so far indications show that the WM is responding well.

As someone currently undergoing treatment as part of a clinical trial, I would recommend to anybody to consider it as an option if it is a possibility for you.

The research nurses on my trial are fantastic and I notice extra tests and checks. For example I have a chest and lung function test prior to treatment as part of the clinical trial protocol and also a one-to-one with the pharmacist to discuss the medications in detail. I really feel part of something.



If you would like to share your story, please get in touch. We welcome stories from people from all backgrounds, communities and experiences, so that we can reflect the diversity of lymphoma stories better.

To share your story get in touch at publications@lymphoma-action.org.uk

Emotional wellbeing and mental health



Angela Waind, Consultant Counselling Psychologist, talks about emotional wellbeing and mental health.

Research shows that people living with a health condition are about 30% more likely to experience anxiety and depression. When we consider how much a lymphoma diagnosis impacts all aspects of life, that figure isn't surprising.

If you are living with a lymphoma diagnosis, understandably you may find yourself focussing on the physical side of your health - symptoms, treatment or side effects. But for good health and wellbeing we can't separate physical and mental health.

We experience this link between our physical and mental health in the natural way our brains deal with stress. To keep us safe our brains trigger fight, flight or freeze responses, which all have physical effects. For example, before a follow-up appointment many people feel anxious or stressed, which can lead to physical sensations: a knotted stomach, or feeling sick or dizzy. It's not only the person with lymphoma who experience this, but family, friends and carers experience it too.

Is lymphoma particularly challenging?

Whilst all cancers come with uncertainty, lymphoma and other blood cancers are different because they can come with more uncertainty. People whose current care is active monitoring, for example, know they have a cancer but without the certainty of having active treatment or a treatment plan. Understandably, this can make things feel out of control and uncertain.

Many people worry about their cancer progressing or relapsing; these fears are completely normal, with about 5 out of every 10 people who have a cancer diagnosis reporting this as a major concern. Family, friends and carers very often share these worries and fears too.

It can be helpful to talk about these fears, and just voicing them can make a huge difference. Living with the effects of a lymphoma or blood cancer diagnosis and taking care of your health can be challenging and confusing. Often you are advised to check for lumps or other symptoms, and this can lead people to worry more. Talking about these concerns and discussing practical ways of managing them can help you, your family and friends to consider ways to take care of your physical and emotional health.

Coping with stress

The thing I notice most is just how many strategies people already have to cope with stress. These are things that people do so naturally they have stopped noticing them. It can be helpful to think about or talk about the things that used to help before lymphoma and consider whether they might still be useful, or whether they can be adapted in some way.

If exercise was something that helped with stress or worries before you were affected by cancer, you may find you can still use that strategy. Your physical health may mean that you can't exercise the way you would like at present, perhaps like long runs or going to the gym, but you may still be able to be active by going outside and talking a short walk. Noticing all of these achievements is really important.

We don't think twice about telling someone we care about to take things easy or to do something that they enjoy. But when it comes to ourselves we often apply a different, harsher set of rules.

The other thing I would say is that we often forget to be as kind to ourselves as we are to other people.

Making a 'to do' list which starts with three or four recharge points each day can help you to be kinder to yourself. These recharge points are small things that you enjoy or that are important for you spread throughout the day. These might be taking time to sit with a cup of coffee for 5 or 10 minutes, talking to a friend, listening to music or sitting in the garden. Many people find short mindful exercises or taking time to notice sounds or sights more intensely work well to recharge them. These brief recharges can help to switch attention away from worried thoughts to something you enjoy. This can give you a bit of a boost and start to lift your mood.

When do you need to ask for help?

If you have never been concerned about your mental wellbeing before, it can be difficult to recognise when you are struggling or when things don't feel right. Whilst the impact of lymphoma means feeling low, anxious or depressed is normal and understandable, help is available and there are key things that indicate that it may be the time to accept help:

- If you find that your brain is so busy with worried thoughts that it is stopping you from concentrating on things like talking to your family, reading a book or focussing on a TV programme.

While your medical team can help with your physical wellbeing, it is you who can identify when things are proving difficult emotionally.

- If you have stopped doing things that you usually enjoy doing because you struggle to feel motivated and don't think you would enjoy them.
- If you find you are cutting yourself off from people because you can't face seeing them or don't know what you would say, or if you are putting off doing things that would have given you pleasure in the past.
- If you find you need to speak to your medical team a lot to be able to get reassurance to manage your worries, especially if the reassurance doesn't last very long.

How do I start a conversation with my medical team?

Throughout your care you will have the support of a healthcare team who want you to have the best health and wellbeing. This team is likely to include your GP, clinical nurse specialist, haematologist or oncologist. Your family and friends are also part of your team. And although people don't always realise it, they are at the centre of their own care team and have a crucial role.



Most of us are good at asking how others are, but it can be hard to start talking about how you feel and what you are worried about. For many people this just doesn't feel natural.

While your medical team can answer questions about your physical health, organising tests and scans to understand what is going on physically, they can't identify what is going on with your emotional wellbeing and mental health. **That is the part that only you can contribute to your care.** This is why it is so important to speak up and let your team know when things feel difficult.

No one will be surprised if you are feeling anxious, low or you are worried about what is happening to your body. They will expect you to tell them if things are difficult and will be glad you are sharing that information with them. It will mean that they can help you get the right support.

Should I share my concerns with my friends and family?

If you have a support network around you, they will want to help. Often friends, family and carers feel helpless; by talking to them, asking them to listen and telling them what you need or what would help, you are giving them a way to help you and a job that they can do. By talking through things you are likely to alleviate some of the fear around them and together you may be able to identify strategies. This can be a relief. By talking about something, we can sometimes see things more clearly and often find solutions. Talking isn't limited to family, friends and carers; services like the Lymphoma Action helpline are there to listen if that feels better for you.

What about family, friends and carers. Does this apply to them as well?

It is not only the person who is diagnosed with lymphoma who is affected by the diagnosis, the treatment, the waiting and the uncertainty. It is everyone around them. Family, friends and carers may feel helpless and unsure of how best to help. These things are likely to take a toll on their physical and emotional wellbeing as well.

If you are a carer, it is just as important to be kind and compassionate to yourself and to schedule recharge points. Think about recharges or breaks that you need to be physically and emotionally well enough to

support your loved one. Consider what makes you feel better, whether it is reading a book or magazine, baking or being active. Finding ways to stay connected and be supported is especially important, so meeting up with friends or talking to others is particularly important (even if it has to be virtually).

We often try to protect each other and avoid talking about difficult things, but it is not uncommon to feel scared, low or worried about what is coming next. It can be really helpful to talk about what is worrying you, and it can provide an opportunity to have an open conversation.

People often feel that it is wrong to focus on their own health and wellbeing when someone close to them is living with lymphoma, but it is really important to remember that unless you are physically and emotionally well, you will not be able to look after your loved one.

What services and support are available if you are concerned about mental health?

There are lots of support options available. Clinical nurse specialists understand the kind of emotional wellbeing struggles that people might be having in relation to their lymphoma and are trained to provide support. Your GP can also direct you to community support and to talking therapies such as cognitive behavioural therapy which is available through 'Improving Access to Psychological Therapies' (IAPT).

Your GP or CNS can refer you to specialist cancer psychological therapy services or clinical health psychology services linked to oncology and haematology services. These services are often based at GP surgeries or local health centres.

In many areas, you can self-refer, but your GP or any member of your healthcare team will be happy to refer you too. Speak to your GP or your clinical nurse specialist and they will help to navigate you to the best help for you.

Life in a pandemic

It has been a really difficult year and most people are struggling with the uncertainty of living with COVID at the moment.

Many of the things that we use to support us have changed. We can't see people face to face and it's difficult just to go out, and we don't know how long this will last. I have noticed that lots of people who are affected by cancer have found they have managed with the pandemic and restrictions better than other people they know. This might be because people with lymphoma are used to living with uncertainty and managing their health and wellbeing in difficult circumstances. Often they have been able to support others by sharing the strategies they have developed. People affected by cancer are also noticing that because everyone is currently experiencing uncertainty and restrictions, the people around them are able to understand more clearly the challenges of living with lymphoma.

To hear more from Angela, listen to her podcast at lymphoma-action.org.uk/LymphomaVoices or share.transistor.fm/s/5a30e106

If you'd like to talk about what's happening for you, please call our freephone **helpline** on **0808 808 5555** (weekdays 10am to 3pm). The helpline offers information, emotional support and a confidential listening ear.



Imtiaz talks about his diagnosis of central nervous system (CNS) lymphoma

I'm Imtiaz and this is my cancer journey. I call it a journey because with luck, perseverance and self-determination, I am not simply the passenger, but the driver.

Nearly 3 years ago, when I was 46, I was diagnosed with an aggressive non-Hodgkin lymphoma in my brain. The symptoms had been there for about six months: I had become forgetful and was constantly feeling tired. I honestly have no recollection of this period.

The diagnosis was mind-blowing, but I didn't panic. Getting cancer is not what I would wish on anyone, but I have learnt so much about myself through this.

I was told I would need to start treatment with chemotherapy almost immediately. As I sat on the hospital bed I realised how real it was. I looked around the ward and saw that it was filled with men of all ages, all of us sharing the same reason for being there. Over time I got to know some of them, as well as the clinicians and healthcare teams.

I have been asked how I coped, especially as mine was a particularly difficult type of lymphoma to treat. The truth is that I was 46 years old and had a good life with a fantastic partner, amazing brothers and sisters and a wondrous mother who has sadly passed but had inspired me with her fortitude and strength. I had a great family. Compared with the younger people I met who were dealing with their own treatment, I felt that I had been so fortunate to have got this far without a major illness. It made me appreciate more than ever what I had.

During chemo I had no appetite and I could feel my body reacting to it. Looking at my fingers, the skin on them was tight like sausages and my body and face swelled up. I had horrible diarrhoea and I was always tired, but I knew I had to take it.

Sometimes I would go out for fresh air and sit outside the hospital, still attached to a drip. I'd watch the people go by in cars, buses, cycling or on foot. I thought to myself how lucky they were just getting on with their lives.

My partner Aga was amazing. She'd get up at 6am to go to work and then come to see me in hospital at 6pm and stay until 9.30pm. I have six sisters and two brothers and my wonderful family would come and visit; the pick-up they gave me was amazing.

In the latter part of my treatment I was told I would need a stem cell transplant. Stem cells come from the marrow in your bones. In my case they drilled into my pelvis to extract them which I have to admit was painful. As my final chemo would destroy my immune system, the stem cells would eventually provide me with a new immune system. But as my immune system was rebuilding itself, it would also make me vulnerable to catching infections.

My fourth and final chemo was the strongest, causing my hair to fall out and a lot of sickness. My weakened immune system meant that I had to avoid infections, so I spent a month on an isolation ward.

In this ward there was a brass bell with a plaque that asked patients to ring it three times when their treatment is complete. It was a signal to the other patients that they too could do it.

My treatment continued, but at the end the consultant said I was free to go. It didn't really sink in. My cancer was gone.

Only as we were leaving the hospital, I realised there was something I needed to do. I walked to the bell, took hold of the string and gave it the loudest clang I could. I wanted to let the other patients know I had made it. The doctors and nurses came into the corridor to see who was walking out and I can't express how grateful I was for their help.

Stepping out of the hospital was a lovely sunny day, but I felt low. I was questioning why it was I was allowed to survive. I learnt from the nurses and counsellors that this is known as 'Survivor's Remorse' and is when you are filled with guilt for making it through.

The weeks passed and I could not shake off this low feeling. I was referred to a Macmillan counsellor. I think having it explained to me helped enormously. Returning to my family home was an amazing time and being there with all my brothers and sisters was magical.

Finishing cancer treatment was perhaps the easy part. My whole body and mind had tired. The Macmillan counsellor said it can take years to get back to my original mojo level as everyone is different. I'm getting there.

What this experience taught me was to appreciate life, music, nature and everything around me. It has also taught me that although we may fall out with each other over stupid things, it is important to iron things out.

I have been in remission for about two and a half years. I know that my cancer can come back. If it does, I'll be ready.



Remembering a loved one with a Tribute Space

June explains how setting up a Tribute Space in her husband's memory provides a great comfort.

When my husband passed away, only 3 months following diagnosis of his condition, it was such a terrible shock. All my energy was focused on keeping his memory alive for myself, my family and friends and at the same time supporting Lymphoma Action.

I had used Lymphoma Action's services as soon as my husband had been diagnosed with a very rare form of lymphoma.

Following his death I began running, initially 5k and then 10k runs, and wherever I had the opportunity I was raising funds for the charity. The Tribute Space has provided a wonderful way of being able to continue to fundraise in my husband's memory since 2014.

I love the candles that can be lit, which I usually do on the date he passed away and also for his birthday. The page also allows me to see the amount of money that I and others have raised, which is such a thrill, and something I know he would be so proud of.

The Tribute Space is easy to use and lovely to share with others.

They are a great comfort for people who may not be able to visit where their loved ones have been buried. In this way, they can still contribute and feel a sense of involvement, which in the current circumstances is very important. There is also the option of adding photos, music and messages too.

Tribute Spaces are a safe and comforting place that bring the opportunity to quietly reflect and remember loved ones. I would definitely recommend setting one up.

If you would like to discuss setting up a Tribute Space in memory of a loved one, please contact us on **01296 619400** or fundraising@lymphoma-action.org.uk. For more information visit our website at www.lymphoma-action.org.uk/Tribute

Leaving a legacy

If you would like to discuss a legacy in memory of a loved one or leaving a gift in your will, please contact us on **01296 619400** or email

fundraising@lymphoma-action.org.uk
For more information visit our website at www.lymphoma-action.org.uk/Legacy



Enter our prize draw so that we can continue to support people like Marie

The Lymphoma Action Prize Draw is a great chance to support our work and make a difference to the lives of people affected by lymphoma.

Marie reached out to our UK-wide closed Facebook support group, Lymphoma Action Support UK after her diagnosis of B-cell high-grade non-Hodgkin lymphoma in 2020.

'In the early stages I had no idea what lymphoma was or what to expect, and the numerous scans and tests sent me into a state of panic. However, the support of others who have been affected by lymphoma has been a massive help to me emotionally. My questions were soon answered by others on the Lymphoma Action Facebook group, and they very helpfully pointed me towards Lymphoma Action's publications and online webinars. The information that the charity provides is invaluable, and the good news stories that I hear in the group also keep me positive and focused on the finish line!

I can't thank Lymphoma Action enough as without their support the journey would be far more challenging and the mountain harder to climb.'

Marie



Take part in the Lymphoma Action Prize Draw, and help us give much needed support to people living with a lymphoma diagnosis.

Every ticket bought helps us to continue our work ensuring that no one faces lymphoma alone. Please visit lymphoma-action.org.uk/PrizeDraw to find out more, call the Fundraising Team on **01296 619419** or email fundraising@lymphoma-action.org.uk

The value of art

As part of our 35 year anniversary, Lymphoma Action are focussing on 'positive mental wellbeing'. David explains how art and creativity became important after his treatment for relapsed diffuse large B-cell lymphoma.

I was treated in 1995-96 with chemotherapy and a stem cell transplant, and am delighted to report that I have been clear of lymphoma ever since - 25 years! Looking back, it was a very difficult period of my life and I am very grateful to a lot of people; the doctors and nurses, my parents, colleagues and students, and also Lymphoma Action (Lymphoma Association back then) which was a constant source of reassurance and encouragement.

The other person by my side throughout was my future wife, Ann. She looked after me throughout my treatment, travelling to Leeds from Hull twice a week to visit me in hospital and caring for my every need when I was allowed home. We bought a house, not knowing how long my future would be. In September 2018 we finally got married, much to the delight of family and friends.

I retired nine years ago having worked as a science teacher/lecturer. After treatment I decided I wanted to explore the arty side of my life: painting, sculpting, etching, making papier mache dinosaurs with grandchildren and so on. Ann also took the opportunity to retire and started writing children's books, which I illustrate and we self-publish.

I was recently asked to produce some work for an exhibition and decided to document my cancer experience, which I called 'The Emotions of Cancer'. This is a self-reflective piece showing my facial emotions from diagnosis to remission. The faces are set on a backdrop of some treatment experiences and thoughts, all washed by mood colours.

David's art will be displayed at the St James's University Hospital, Leeds art collection.

A day in the life of our Live your Life coordinator Nika

Our Live your Life coordinator, Nika, gives an insight into her role at Lymphoma Action.

I coordinate the Live your Life workshops for Lymphoma Action. These are free one-day events for people at the end of treatment or on active monitoring.

I joined the events team in the spring of 2018. At that time, it was typical for me to arrange workshops all over the UK: filling a room with people who were both nervous and intrigued as to what the day had in store for them. Since then, the way in which we deliver the award-winning programme has changed, as now it is delivered virtually.

Live your Life workshops aim to help people take control, and orientate themselves within their 'new normal', and help people to improve their wellbeing and quality of life. They are also an opportunity for people to meet others in a similar situation to their own. Individuals are encouraged to bring a family member or friend with them, for support.

Around 20 people attend each workshop.

In 2021 I hope to deliver 25 workshops with the help of a fantastic group of volunteer facilitators.

A key part of my role is liaising with clinical nurse specialists (CNS). The CNS plays a crucial role in connecting our charity to people who are finding their way through the complexities of lymphoma and may not yet be aware of the support Lymphoma Action provides. The CNS is the route by which most people hear of the workshops.

I often receive calls from people who have heard about the workshop, but don't know what to expect. They are often concerned about a day sat in front of a device screen. After attending however, most have said that it 'worked surprisingly well over Zoom.'

My favourite part of the day is when volunteer facilitators reveal that they also have lymphoma. From then on, I feel people understand the tone of the workshop.

Workshops are inclusive and interactive, rather than being one in which an expert will talk all day.

On workshop days my role includes ensuring all technical elements work well. At times, I wish I had another set of arms and at least two more pairs of eyes to be sure the different functions are running smoothly!

I love the feedback at the end of each workshop because those who attend come away from the day having gained value. The most common feedback is that people no longer feel that they're the only one living with the unique and complex challenges of lymphoma.'

If you or someone you know would like to attend a virtual Live your Life workshop, contact Nika on **01296 619434** or email **a.bass@lymphoma-action.org.uk**. Details can also be found at **www.lymphoma-action.org.uk/LYL**



Services and support available for you

During the COVID-19 pandemic we are not able to run our usual face-to-face events. However, we have online services and support to keep you connected during this time.

Catch up on webinars and videos

We have recorded over 20 webinars and videos on topics ranging from COVID-19 vaccinations, personal stories, wellbeing, coping with fatigue and many more.

Watch our COVID-19 webinars and videos at lymphoma-action.org.uk/Covid19Videos and wellbeing webinars and videos at lymphoma-action.org.uk/Wellbeing-Videos

Attend a Live your Life workshop

On page 33, Nika explains more about our self-management workshops designed for people who have finished treatment or are on active monitoring (watch and wait). They aim to help you to take control, and to improve your wellbeing and quality of life. The workshops are run as one-day, interactive online events.

Find out more at lymphoma-action.org.uk/LYL

Helpline and Buddy Services

Our Helpline Services offer information, emotional support and time to talk in a confidential environment. You can contact by phone (freephone **0808 808 5555**), email or Live Chat (via the website) weekdays from 10am to 3pm.

Our Buddy Service aims to put you in contact with a Buddy who has been through a similar experience, and can give you support, whether you have lymphoma or are a family member, friend or carer. Contact our helpline to find out more.

Join our online support meetings

Our online support meetings are opportunities for people to share experiences and provide mutual support. We also have groups for young people, and for family, friends and carers. They are hosted through Zoom, usually on a monthly basis, and last an hour.

For more information or to join an online support meeting, visit lymphoma-action.org.uk/online-support-meetings

Our Facebook group goes from strength to strength...

If you'd like to connect with other people affected by lymphoma why not join our UK-wide Facebook group? The group offers support and connection.

You can join by going to facebook.com/groups/LymphomaActionSupportUK

Our 2020 survey shows why so many people have found the group a vital support.

What difference has the group made?

"You have helped me more than you will ever know!"

83% - feel more informed from joining the group

75% - feel more supported

63% - feel like someone understands

57% - feel less isolated

57% - feel more reassured

 **1.4K**
members
(and growing!)

'It has helped me to understand my illness and taken away a lot of fear. I am so grateful for all the support I have received.'

What's your lymphoma connection?



90%

would recommend the group to others

'One of the best self help groups. I have met many people who can empathise.'

Our amazing fundraisers

A huge thank you to all our 2020 fundraisers for the tremendous amount of money you raised last year. Your support makes it possible for us to provide the services on these pages, as well as our website, Clinical TrialsLink, videos, webinars, podcasts and our award-winning books.

Highlights of last year included Bridges of Britain, which saw 119 people walk across bridges around the UK, raising almost £33,000.

Our seventeen virtual London Marathon runners raised over £17,000 and our Santa Run attracted 117 runners, raising almost £25,000. We heard how much people enjoyed the virtual Balloon Race, with 295 people taking part, as well as many other fundraising events during the year.

To find out how you can get involved in 2021, see pages 14, 15 and 21.

Our volunteers continue to make a huge impact

Volunteers are at the heart of much of our work. They support us in so many ways, from reviewing our publications to facilitating workshops and support meetings, being a buddy and raising funds for us in their local community, as well as a multitude of other activities.

The past year has been a very different time for volunteers, and many have been unable to perform activities as before. However, as an organisation we have adapted. We've taken our support meetings and Live your Life workshops online. We've launched micro-volunteering activities, a new Insights Panel, and we've recruited new Buddies. This meant that our volunteers were able to give over 2,000 hours of their time last year despite being unable to go out and about.

If you're interested in joining us, you can enquire about opportunities in your area at lymphoma-action.org.uk/Volunteering



A massive thank you from all of us at Lymphoma Action for all that you do!