

lymphoma matters

ISSUE 122 | SPRING 2022



Lymphoma
action



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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for over 35 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment, and aftercare of lymphoma. We're here for you.

Views expressed are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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Cover: Ian, who shares his story on page 30.

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

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

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

With thanks to AbbVie, Kyowa Kirin, Takeda, Bristol Myers Squibb and Incyte Biosciences UK Ltd for funding this issue of *Lymphoma Matters*.

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

Lymphoma action



Ropinder Gill
Chief Executive

Lymphoma Matters has come in a different cover this time while we test a few different things to see if we can make our mailings more environmentally friendly.



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](#)

Excited by the opportunity to do even more

January and February are when we reflect on the year gone and look forward to our plans for the coming year. 2021 was dominated by the rollout of COVID vaccines, which was positive, but also created many questions and uncertainties. Our role was to provide clear information and support throughout. As a result, we've seen more people use our services, more people visit our website and more join our online meetings. You can read about what your generosity helped us achieve on pages 13-15.

I'd like to mention two particular highlights. In the last weeks of 2021 we received our largest legacy to date. This unexpected gift was given in recognition of our helpline services. It will be used carefully, like all of our funds and legacies, to honour the generosity of the donor. We never know exactly how our legacy income will pan out, which is why legacies can be so transformational, allowing us to develop services and activities. Every legacy is important to us, no matter how small or how large.

The second highlight was that the Lymphoma Coalition (a global coalition of lymphoma charities) awarded the Karen Van Rassel award to Lymphoma Action in recognition of our information and support through the pandemic. This prestigious award recognises the tremendous achievements in the global blood cancer community and was a fabulous achievement for all of our staff. You can read more about this award on page 4.

We know that this year will bring its own challenges but we are excited about having the opportunity to do even more for you. COVID-19 has had a huge impact on the NHS and could have a far-reaching impact on the treatment and care of lymphoma. Not only do we want more people to benefit from our services, but we also want to do more to effect change and influence these developments.

None of this is possible without our lymphoma community, so thank you for your support.

**Ropinder Gill
Chief Executive**



Lymphoma Action wins global award

We were delighted to be awarded the Lymphoma Coalition's 2021 *Karen Van Rassel Leadership Award*. The Lymphoma Coalition is a worldwide network of over 80 patient groups in more than 50 countries.

Formed in 2002, it provides support to people with lymphoma globally by sharing resources, best practices, policies and procedures.



In the words of the Lymphoma Coalition, the Karen Van Rassel Leadership Award was awarded to Lymphoma Action in recognition of their work during the COVID-19 pandemic including:

- Responding quickly and effectively to the global crisis, expanding their efforts, and modifying programmes to address the issues the pandemic caused for those affected by lymphoma.
- Ensuring people with lymphoma and their loved ones had access to the most recent information on COVID-19 and its impact on their care.
- Working collaboratively with charity partners to influence policy and advocate on behalf of people with lymphoma.
- Modifying their services to support healthcare professionals whose work was deeply impacted by the pandemic.
- Focusing on how they can help alleviate health inequalities, an issue exacerbated by the pandemic. Lymphoma Action are actively working to improve their services to support those who may find connecting with Lymphoma Action more of a challenge.
- Taking care of their staff team by ensuring practices were in place to protect them from COVID-19, but also adding resources and supports to help them with their wellbeing.



Lymphoma Action Chief Executive, Ropinder Gill said: '*We're delighted to get this award. The pandemic has been tough for those affected by lymphoma and for our staff. I am so proud of how the team here have worked to provide the best information and support that they could, driven by a real focus on the job we're here to do for people affected by lymphoma. This is a lovely recognition for all that work.*'

Lymphoma Action plans for 2022

This year we are looking forward to further developing our services for people affected by lymphoma across the UK.

This means more peer support, information, top tips, videos, webinars and podcasts, amongst other things. Our aims are:

- to develop a hybrid approach to service and information delivery through a blend of face-to-face and digital services, and hard copy and digital publications
- to improve accessibility of services and information by building on study findings, user feedback, and best practice in equity, diversity and inclusion
- to increase our reach through promotion, raising awareness, and education events, and considering specific groups such as clinical nurse specialists, parents, carers and families
- to provide a meaningful volunteering experience that enhances our service delivery by improving recruitment, induction, training, and supervision
- to understand the needs and preferences of our users through surveys and feedback
- to support and develop staff, building capability through experience, training and team working.



We hope you join us throughout the year as we continue to provide our range of services so that no one faces lymphoma alone.

Dallas Pounds, Director of Services

New book on CLL and SLL

We teamed up with Leukaemia Care to bring a new information book for people affected by chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL). It covers diagnosis and treatment, as well as tips on living well and finding further support. This book also includes quotes from people with lived experience of CLL or SLL.

Download:

lymphoma-action.org.uk/Books

Order a copy free of charge:

lymphoma-action.org.uk/Shop

The image shows the front cover of a book titled 'Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)'. The cover is teal and white, with the title at the top and 'Leukaemia Care' and 'Lymphoma Action' logos at the bottom. To the right of the book, there is a purple graphic area containing text and a quote.

Lymphoma Action
Inform | Support | Connect

“ Clear and comprehensive with lots of useful info and signposting to more detail – a great resource!

- Doreen, affected by SLL

The role of the pathologist in the diagnosis of lymphoma



An accurate diagnosis is essential to ensure the right treatment is given. In a recent podcast, we asked Consultant Haematopathologist, Dr Bridget Wilkins, to answer some of our most commonly asked questions about pathology and the diagnosis of lymphoma.

What types of biopsies are there?

Many people will have had a **cytology test**, which is sometimes referred to as **fine needle aspiration**, where a very fine needle is inserted into an enlarged lymph node and cells are sucked out as a liquid sample. The cells are spread on a slide and sometimes this quick and easy test can be enough for a diagnosis.

A **needle biopsy** may be used if there's an enlarged lymph node at a superficial site, for example, just under the skin in the neck or armpit. It is called a needle biopsy, but it's like a very tiny apple corer that takes a mini cylinder, or core, of tissue out of the lymph node. This process is also quite easy to do and can be enough for a diagnosis.

The remaining types of biopsy are a little more involved, and often need the person to have a general anaesthetic.



These biopsies are performed when removing a whole lymph node or when access to a node that is deep inside the body is required, so a surgical procedure is needed. Biopsies in which whole tissue is removed are referred to as **excision biopsies**.

Sometimes it is not a lymph node that is being sampled, even though the suspected diagnosis may be lymphoma. It may be at another body site, as occasionally lymphomas arise in the stomach, bowel, lung or bladder. Those would be biopsied in the same way as other suspected cancers, with something called an **endoscopic biopsy**. In this procedure, the endoscopic tube is inserted and a sample is removed using a small set of cutters within the instrument.

Occasionally, lymphoma can be found in organs like the salivary glands, which lie in the tissue under your cheeks. These cannot be removed, and they are not easy to take a needle core from.

They are sometimes sampled using an **incisional biopsy**, where a small sliver of tissue is taken and the skin is then sewn up.

A **bone marrow biopsy** may be taken if we want to stage a lymphoma to see how far it has spread. This is also taken using an apple core type needle, with the sample being taken from the pelvic area around the hips, usually at the back.

How is the type of biopsy decided?

Because cytology tests (fine needle aspiration) and needle biopsies can be done as outpatient procedures, they are often much quicker to arrange, since you do not have to wait for a surgical procedure. They are also less intrusive as they remove less tissue and are simpler procedures for someone to go through. So they are done for convenience and speed, but might also be performed if a patient is too unwell to have a general anaesthetic.

As long as the procedure has gone well and has yielded plenty of the material it was aimed to collect, then there should be enough to make a diagnosis. However, there will be very little of the sample left after investigation to come back to later, which can be helpful to have.

Are biopsies needed for all lymphomas?

There are a few lymphomas that at the time of diagnosis have spread into the blood, and so a blood test might confirm a diagnosis. A typical example would be chronic lymphocytic leukaemia (CLL), maybe mantle cell lymphoma and a few rarer lymphomas. But in almost all other circumstances you do need some sort of biopsy to confirm the diagnosis. The only caveat to this is if you already have a diagnosis of lymphoma, have undergone treatment and there is a suspicion of relapse, then you

don't always need to have a re-biopsy. Often imaging studies and other tests done with the blood can be enough to know if the lymphoma has come back or not. PET scans are good at showing if disease has recurred.

What happens to the biopsy samples?

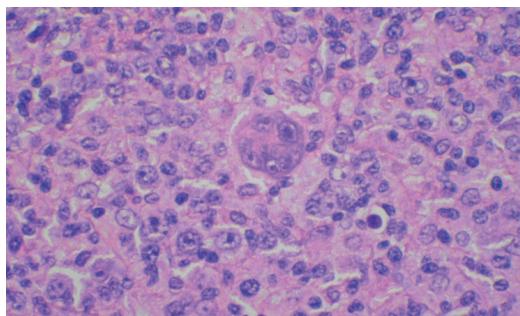
For liquid samples, such as blood samples and fine needle aspirates, the sample might need to be spun in a centrifuge (which is a device that separates various components of a fluid) or it might need an immunology agent for microscopic analysis. It might also go through instruments like a flow cytometer where cells can be characterised by their phenotype (form and structure).

If we have an aspirated cytology sample, it can just be shaken to give an even suspension of cells that can be treated with specific stains and examined visually. Some of the sample could be sent to be phenotyped or for genetic tests.

Solid samples take a bit more handling. In most cases, we aim to preserve the sample forever whereas the liquid samples are gone once they have been used. The needle cores are placed in a liquid called fixative that is usually formalin. That stops it from breaking down because of bacteria in the environment. We have to make it suitable for staining so that it can be viewed under the microscope; to do this we have to remove all the water. We do this by replacing the water with alcohol, then we replace the alcohol with another solvent, which can mix with wax. This has the advantage that the wax is hard, so instead of a soft, fragile sample, we have something that is hard, robust and storable. The wax embedded material can be sliced very thinly and it is those slices that are mounted onto the microscope slides and stained. Stains help to characterise the cells.

What is the role of stains in biopsies?

Stains highlight both the usual and unusual. They are the same as we use in other tissue types for diagnosis, not just lymphoma. The basic stain that we use is called H&E which is actually a combination of two stains, hematoxylin (a purple dye that stains the nucleus) and eosin (which stains the cytoplasm of cells pink or orange/red). H&E is the most widely used stain in medical diagnosis. When we prepare the tissue in wax, it has no colour, but once we add H&E we restore visibility.



Hodgkin lymphoma cells with H&E

How long does a biopsy result take?

The length of time it takes to get the results following a biopsy can vary quite a bit. If we have a fine needle cytology specimen, where we have sucked out cells, spread them on a slide and been able to look at that with a very simple stain, then the result could be available within a matter of minutes. However, that is not usually a definitive result because to do the next step, which would give us a more definitive diagnosis, we would need to do immunophenotype characterisation. Immunophenotyping identifies certain surface molecules on B cells or T cells alongside analysing the physical characteristics of cells. These tests take about half a day to perform. The turnaround time is longer for tissue samples that need to go through the fixation process, since this process itself takes around 8-12 hours.

In general, the time it takes to get a result can depend on a number of things:

- The workload of the laboratory.
- The hospital where the sample was taken, as haematopathologists often work at big centres or teaching hospitals and so may be a distance from the hospital where the biopsy was carried out. It is important to note that samples will always go into a fixative straightaway and may be processed into the wax tissue blocks in the hospital where the biopsy is taken, so that cells are not affected in transit.
- It might take longer to get a diagnosis if it is not straightforward; some lymphomas are easier to diagnose than others. The more we need to do to make a diagnosis, the longer it is going to take. If we need to do a lot of immunophenotype characterisation with extra stains, or if we're not sure that it is lymphoma at all, then that may need molecular tests and those can take two weeks or, occasionally, longer.

As a pathologist, what are you looking for?

At a basic level, I am trying to see how the sample compares with what I would expect to see normally. I am very familiar with what a normal lymph node, bone marrow and the other tissues in the body should look like. I also look to see if the sample appears different, and if so, in what way? What is happening to individual cells? I also look at the structure and architecture of the node. Lymph nodes normally have a well-defined outer edge, a capsule that holds the whole lymph node in, and I'm looking to see if it is intact or whether something has eaten its way into it. A normal lymph node is made up of little nodules or follicles and I'm looking to see whether there are follicles and if not, why not? What has replaced them? Are they normal, or abnormal?

I also look at individual cells in fine detail. Are the cells mainly small, mainly large, in between, a mixture, or are there rare cells, for example Reed Sternberg cells, which might point to a specific diagnosis such as Hodgkin lymphoma.

Small cells tend to indicate a slow growing lymphoma and large cells tend to suggest a faster growing lymphoma. This is an oversimplification but is sometimes helpful to know if other tests to reach a final diagnosis are going to take a while.

What tests do you perform on the sample?
Staining with H&E will provide a basic assessment of cells size and architecture, and this tells us 50-90% of what we need to know. But on top of that we need to do immuno-stains. People may have heard the CD numbers that are mentioned in relation to lymphoma (eg CD20). These identify surface molecules on B cells or T cells, and are present in specific combinations for certain types of lymphoma. We have a whole panel of immuno-stains to recognise the right combination for the right diagnosis. If they don't match, then it would make us question the diagnosis.

With immuno-stains, we have around 90-100% of the information we need to make a diagnosis. The extra might require molecular tests in a small number of cases only.

Do you look out for conditions other than lymphoma?

One of the key roles of a haematopathologist is to be aware of other diseases that can occur in the lymph nodes. It could be that a suspected diagnosis of lymphoma is incorrect and the person has some other disease causing the lymph node to be enlarged, such as tuberculosis (TB).

We have to consider metastases, for example from breast, bowel or lung cancers, but these look very different so are fairly easy to rule out. We consider autoimmune conditions, such as systemic lupus erythematosus, which can cause us challenges in diagnosing lymphoma. We take a lot of care to look out for other conditions, as we really don't want to start treating someone for lymphoma if they don't need it.

Are biopsy findings always correct?

People should be reassured to know that we don't just look at the biopsy samples in isolation. We have access to blood results, imaging pictures, results of the examination by the doctor who has seen the patient and, most importantly, the person's clinical history. If this information, together with the histology, all matches up, then we get a diagnosis.

Are results double-checked?

It is not a mandatory requirement that two pathologists report on a lymphoma specimen. We do tend to work in teams, though, and for difficult cases, we would consult with our colleagues and share the diagnostic process. In any multidisciplinary team (MDT) meeting for lymphoma, a pathologist will be a core member of the MDT to discuss and present the pathology findings, and discuss how they fit with the other findings.

**With thanks to Dr Bridget Wilkins,
Consultant Haematopathologist at St
Thomas' Hospital, London and Royal
Hampshire County Hospital, Winchester**

**Listen to Bridget in conversation at
[#BridgetWilkins](https://lymphoma-action.org.uk/podcast)**



Affecting my mind, my work and my body

Colin talks about his diagnosis and treatment for primary mediastinal large B-cell lymphoma, including applying for Personal Independence Payment (PIP).

In December 2017 I was 49 and a full-time volunteer supporting asylum seekers and refugees, helping at a food bank, running a community garden and trying to set up a local, community-led nature reserve. Life was busy and I felt fortunate never to have had a major illness.

Just before Christmas 2017, I started to have a funny feeling in my head. It wasn't a headache, more a tightness. Although it worried me at the time, it went away. I decided to see my GP after it happened a couple more times and my doctor thought it could be something as simple as ear wax.

A few days later I experienced dizziness and my face looked swollen.

I went back to the GP surgery and saw another doctor who thought it could be labyrinthitis (an inner ear infection that affects your balance) and was prescribed some medication. Things didn't improve and one Sunday I felt so ill my wife called an ambulance. In A&E they did tests on my heart and carried out a chest X-ray, all of which seemed to indicate that nothing was wrong.

Four days later I passed out on the landing at home. My wife called 111 and they called an ambulance, despite it being in the middle of a blizzard. In A&E the medical team picked up a note in my file from a radiologist who had reviewed my X-ray asking that a CT scan be done. Over the next three days I had tests, a biopsy and more scans.

I was diagnosed with primary mediastinal large B-cell lymphoma (PMBCL) and was told I had a growth the size of a large lemon in my chest which was growing really fast.

I started chemotherapy with one dose of R-CHOP, followed by six doses of DA-R-EPOCH. This is a similar regimen to R-CHOP but includes etoposide, which they thought would help with the fast-growing nature of my lymphoma. Because I was relatively young and fit, they felt I would be able to tolerate the more aggressive chemotherapy, and DA-R-EPOCH is one where the dose can be adjusted, meaning they could increase my dose if I was tolerating it. It has to be given via a Hickman® line which meant I had to be in hospital as an in-patient for five days in every cycle.

Between the first and second dose of chemotherapy I started to feel disconnected from my body and nothing felt real at all. I could barely talk properly and was unable to form words. I certainly couldn't put a sentence together. I felt like I was shrinking and that I would disappear.

My medical team referred me to a psychiatrist, as they were fairly sure that what I was experiencing was psychological. They explained that it was a form of disassociation as a result of a dramatic change in my life. I was suddenly facing a life-threatening illness, which involved being an in-patient for at least five days every month, I had to stop work and could not see people because of the risk of infection. All these things were causing me an enormous amount of stress.

I had regular sessions with my psychologist and tried several types of complementary therapy, like acupuncture and aromatherapy.

I don't know how well these worked for me, but I gradually managed to cope and changed my mindset. I had to put my trust in my medical team, and believe what the doctors told me.



I had a lot of side effects from the chemo, which I had been warned about. I had a big head of curly hair and a big beard, but I was told I would lose it. The day before my first chemo, my wife came in with her clippers and cut my hair really short. What I hadn't expected was for ALL my hair to fall out; I don't think a single hair remained on my body. No one tells you how uncomfortable it is without nose hair, and I often had a sore nose as a result. I also struggled with mouth ulcers, which are miserable, and with nausea, which was managed with medication taken shortly before I was due to eat. I became neutropenic and, in the last two cycles, got a serious infection in my Hickman® line, which took a while to control.

Another side effect I experienced, which I wasn't expecting, was cramps in almost every muscle imaginable, including my face and neck and in my jaw when I yawned. I also experienced what felt like cramp in the intercostal muscles between my ribs.

A scan at the end of treatment showed I was in remission, which was what we were hoping for. This was fantastic news and a real relief.

I had been told that once the chemotherapy was finished, I would have radiotherapy as a 'mop up' exercise. This worried me, as I was concerned about its long-term side effects but I have a friend who works as a radiographer who reassured me.

I had 15 fractions of radiotherapy, Monday to Friday for three weeks. At the time, I felt this was fairly straightforward compared with the chemotherapy, but I have developed an underactive thyroid, which I am told is most likely a result of the radiotherapy. I am on thyroxin, which manages this.



It's taken me a while to start feeling like I'm 'firing on all cylinders' but mentally my perspective on life has changed.

I feel I have to live life to the full. Not in a hedonistic way, but trying to live to the best of my ability.

I was encouraged to apply for Personal Independence Payment (PIP) as I was unable to work for quite a while. I left it a bit too long to apply, as I now realise I could have applied much sooner. You have to present a lot of information about what you can and cannot do. I found it helpful to write in my diary a summary of these things on a daily basis. I got help from my specialist nurse, which was extremely useful and I would recommend to people they talk about this as soon as possible. I did get PIP, and in fact it continued for a while after I finished treatment.

It is over three years since the end of all my treatment and I have now been discharged from the hospital, having no sign of recurrence of the lymphoma. I am working and life is looking really promising. It is hard to imagine that almost four years ago I wasn't sure if I would even see the year out.

About primary mediastinal B-cell lymphoma (PMBCL)

PMBCL develops in the thymus and can cause a large swelling inside your chest. It usually affects people in their 20s and 30s, more commonly women. You might have R-CHOP followed by radiotherapy, or you might have a more intensive chemo-immunotherapy regimen. You might be offered treatment as part of a clinical trial.

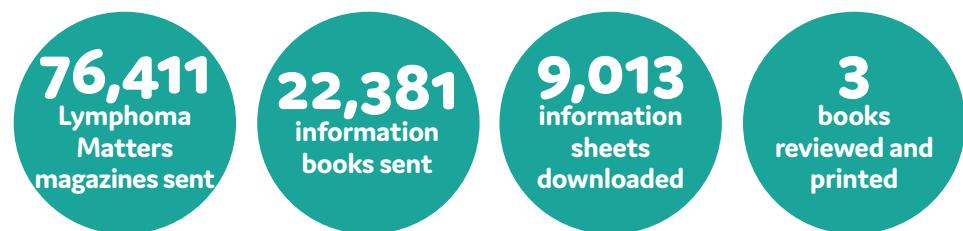
Colin, after shaving his beard and hair before starting treatment. Previous page: before the big shave!

A review of 2021 - our 35 year anniversary

Over the next three pages we show what we achieved in 2021 to make sure no one has to face lymphoma alone.

Information and publications in 2021

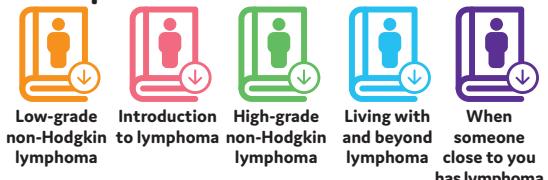
Our award-winning information and publications provide in-depth, expert information for people affected by lymphoma to help them better understand their diagnosis, treatment and life beyond their condition. Below is a summary of our information and publications impact and reach in 2021.



Top five books ordered in print



Top five downloaded books



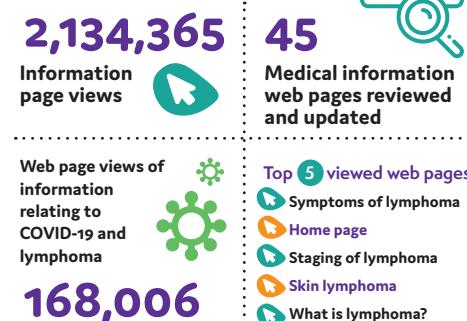
'Thank you for such a great publication. All your resources are excellent; clear explanations and signposting along with hope and realistic reassurance.'

Response to the Autumn/Winter 2021 issue of *Lymphoma Matters* magazine

Lymphoma TrialsLink



Our website



Education and training in 2021

We delivered a wide range of digital information services for people affected by lymphoma, including our Lymphoma Voices podcast series, Live your Life workshops, live webinars, videos, Lymphoma Focus Day and educational events for healthcare professionals. Below is a summary of their impact and reach in 2021.



Healthcare professional education and training

467	healthcare professionals (HCPs) attending three online courses	
1,238	video views from HCPs following live online events	
After attending our Lymphoma Management course:		
94%	said it will help ensure their patients are more informed and understand their condition	
87%	said it will ensure their patients feel involved in managing their condition and making informed decisions	

Live your Life

14	virtual Live your Life workshops
109	people attended virtual Live your Life workshops

After attending a Live your Life workshop:

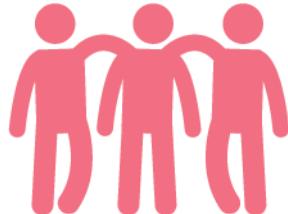
98%		would recommend the workshop to others
92%		said they knew how to look for symptoms of recurrence
85%		said they felt less isolated and more understood
85%		felt that they now know what to do to live well with lymphoma

'Listening to others experiences and how they have coped has armed me with skills and knowledge that will support me on my own lymphoma journey.'

Live your Life workshop attendee

Peer and support services in 2021

Our support services are available for anyone affected by lymphoma whether they have lymphoma themselves or they are a family member, friend or carer. Our services include a helpline, online support meetings, closed Facebook group and a Buddy Service. Below is their impact and reach in 2021.



1,755
Helpline
Service
interactions

2,491
Closed
Facebook group
members

280
online
support
meetings

46
Buddy
links
made

Online support meetings

280
online
support
meetings

1,715
attendees
at meetings



198
new people
joined
meetings

3

Special Focus
Meetings held
(topic-specific
meetings)

75

people
attended
special focus
meetings

Top 5 impacts of the helpline

Individuals:

- felt grateful for the contact
- were able to safely express their emotions
- felt that they were given time to talk
- found the interaction helpful
- were able to develop their own plan of action

Buddy Service

51

Buddy
requests

80

Active
buddies



Closed Facebook Group

7,190 Posts

111,000 Comments

8 Coffee mornings **160** attendees

36 individuals receive 'check in & chat' calls from volunteers each month

'I've found being in this group enormously helpful in the short time I've been here - even just knowing I'm not the only one facing this has helped.'

Closed Facebook group member



Get involved in 2022

Every day 53 people are diagnosed with lymphoma. Do you want to fundraise for Lymphoma Action and help us make sure no one has to face lymphoma alone?

Whatever fundraising you do, our team will be right with you. We provide lots of support and all the resources you might need like buckets, banners and bunting.

April: Lymphoma Action Gaming Challenge

We're 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 or you could organise a relay event or tournament with friends.

Go to our website to find out how to take part:
lymphoma-action.org.uk/gaming-challenge



May and June: Lunch for Lymphoma



Make lunch an extra special occasion by supporting Lymphoma Action!

Host a lunch or teddy bears picnic and charge a small price for attending. How about getting your local school or nursery involved? You could play some fun games, have a quiz – we can provide the questions – or have a raffle. Download a fundraising pack which includes cut-out Bear Ears!

Find out more at:

lymphoma-action.org.uk/lunch-lymphoma

Wonderful treks

Hebridean Way Trek – September 2022

This 9-day challenge will give you the chance to experience the unique island environment, culture and wildlife. You'll be crossing the chain of ten islands off the West Coast of Scotland, from Vatersay on Barra to Stornoway on the Isle of Lewis. Watch out for eagles, seals and dolphins on your way, as well as for archaeological remains along the trail. Our guided trek includes the Highest peak on the Islands, 4 ferry trips and lots of fantastic scenery, plus accommodation. Find out more and register for a place visit:

lymphoma-action.org.uk/HebWay

Hurry, you must sign up for this trip by March to secure your place.



Kenya's Great Rift Valley Trek – Spring 2023

Join #TeamLymphoma for our bespoke, once in a lifetime, Kenya Trek in the stunning Great Rift Valley in 2023. Our Maasai guides will take us 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. Find out more and register for a place visit:

lymphoma-action.org.uk/Kenya

For both these treks the Lymphoma Action Fundraising Team will be with you every step of the way, from ideas and tips for fundraising to being with you on the trip.





Understanding relapse



We put some of your most commonly asked questions about relapse to Charlotte Bloodworth, Advanced Nurse Practitioner at the University of Wales, Cardiff.

Relapsed lymphoma is lymphoma that comes back after successful treatment and a period of remission (no evidence of lymphoma on tests and scans).

Are some types of lymphoma more likely to relapse than others?

Hodgkin lymphoma and high-grade non-Hodgkin lymphoma are more aggressive and are treated with the aim of cure. They tend to be more responsive to treatment so people usually achieve a remission without experiencing relapse.

Low-grade non-Hodgkin lymphomas are slow growing and treatment might not reach all the slow-growing cells. This means low-grade non-Hodgkin lymphomas are more likely to relapse. Some people will be treated straight away if their symptoms are problematic,

while for others an active monitoring (watch and wait) approach will be appropriate.

Although we expect low-grade non-Hodgkin lymphomas to relapse, there is no rhyme or reason to it. Two people could have exactly the same type and stage of lymphoma, and have the same treatment, but one person might relapse while the other won't.

That is also the case with the stage of lymphoma. Because a lymphoma was stage 4 at diagnosis, it does not make it any more likely to relapse than a stage 1 lymphoma.

Is there a period of time after which lymphoma is unlikely to relapse?

Although relapse with Hodgkin lymphoma and high-grade non-Hodgkin lymphoma isn't common, any relapse for these types is likely to happen quickly. The likelihood of relapse for these aggressive lymphomas tends to diminish the further you are from treatment. After about two years, many departments will discharge people, as the risk of relapse is so low.

Low-grade non-Hodgkin lymphoma is treated with the aim of disease control and is more likely to relapse, although it is really unpredictable. Some people might relapse soon after treatment and others never relapse. We also see people who have a few quick relapses and then never relapse again. Some people will be offered self-management, where they get in contact with their clinical team if they have health concerns.

How will I know if my lymphoma has relapsed?

People often ask if the lymphoma will appear in the same place, and whether they will experience the same symptoms as they did at diagnosis. Many relapsed lymphomas will represent in the same way, but it can present differently. These are some of the 'red flag' signs people might look out for:

- a new lump
- weight loss
- sweating
- itching
- fatigue.

People often ask how often they should check for abnormal lymph nodes. I think checking too much can lead to anxiety, but it is really important to know your body. Know what is normal for you and what is not normal, so that you recognise when there is a change.

If you notice any changes, it is important to contact your clinical team, or your GP if you have been discharged. Relapse is rarely picked up in a formal clinical review, which is why patient triggered systems are becoming more common. Clinical teams rely on people reporting any changes, which is why we urge people to get in touch if they have any concerns.

Know what is normal for you and what is not normal, so that you recognise when there is a change.

What tests are needed to confirm a relapse?

As with an initial presentation of lymphoma, a biopsy is usually needed to confirm a relapse of lymphoma. People may have to have re-staging carried out through scans and blood tests.

When lymphoma comes back, does it come back as the same type?

The majority of the time lymphoma will come back as the same type, but very rarely it can come back as something different. If you have a high-grade non-Hodgkin lymphoma, you can have a relapse of a low-grade non-Hodgkin lymphoma. You may not need to do anything about the low-grade lymphoma, but we know this can be very upsetting.

Also, very rarely, you can have a low-grade non-Hodgkin lymphoma which mutates and becomes more aggressive. In this case a biopsy of a suspected relapse will show that the person has high-grade non-Hodgkin lymphoma. This is called 'transformation' and is something we don't see very often. Transformed lymphoma can be tricky to treat, but we do so with the aim of curing the high-grade non-Hodgkin lymphoma. The person will, however, still be left with the underlying low-grade disease.

How many times can relapse happen?

With low-grade non-Hodgkin lymphoma, you may expect to relapse several times, but you can also expect the disease to be controlled several times. This can be over years and decades. I know people who have relapsed several times and still responded to treatment and many people who have had very few or no relapses.

With Hodgkin lymphoma or high-grade non-Hodgkin lymphoma we wouldn't expect the lymphoma to relapse, although occasionally there are people who do. If this happens, there are treatments available.

Are there plenty of treatments available if someone relapses?

People worry that if their lymphoma comes back they are going to run out of treatment options. It is very rare for this to happen in lymphoma.

If someone has a relapse, they often ask if they will be given the same treatment they had initially. Most treatments have diminishing returns (where if you continue to use it, it becomes less effective), so a clinical team may use them again if they worked and provided, for example, five years in remission. However, when using the same treatment again, doctors may predict that it will only last two to three years. Because of this, it is often better to use a different type of treatment if the lymphoma comes back.

As time moves on, more treatments are becoming available, and recent treatments are aimed at being more effective and less toxic than traditional chemotherapy. As a result, there may be something better to use than the original treatment given say five or six years beforehand.

There are also clinical trials for lymphomas that are a bit more difficult or rare and trials testing new drugs. This may be a good option if the mainstay drugs have been used.

CAR T-cell therapy has only been available for the last few years and offers a chance of cure for a second relapse of a high-grade non-Hodgkin lymphoma, like diffuse large B-cell lymphoma or transformed follicular lymphoma.

What would you say to people who are really worried about relapses?

The first step is to acknowledge that worrying is a normal thing. Having lymphoma is a major life event, but make sure that the worry doesn't become overpowering. It is helpful for people to equip themselves with all the information they need, and to be aware of the 'red flag' signs and know what to do if they notice them.

There is a lot of support available, for example Lymphoma Action's helpline, online meetings or Buddy Service. They may also find the Live your Life workshops helpful.

To alleviate worry, it is also important to have some things going on, and by keeping busy, staying active and having things to look forward to. It is also important to allow yourself some time to relax.

Having lymphoma can be a wake-up call and people often tell me that it has changed their priorities. Many people find that it makes them appreciate life in a way they never had before.

The first step is to acknowledge that worrying is a normal thing.

They may reassess what is important to them and I know people who have changed their jobs, while others want to spend more time with their family.

I know people who have had a low-grade non-Hodgkin lymphoma for 20 or 30 years. They echo that they want to encapsulate life, enjoy it and make the best of things.

You can hear more from Charlotte on our Lymphoma Voices podcast at lymphoma-action.org.uk/LymphomaVoices

You may find our Live your Life workshops valuable. Go to lymphoma-action.org.uk/LYL to find out more.

Common signs and symptoms of lymphoma



A new lump (swollen lymph nodes): typically in the neck, armpit or groin.



Weight loss: losing weight quickly without trying to.



Drenching sweats: especially at night and so much that nightclothes and bedding become soaked.



Itching: which might be worse in hot weather or at night.



Fatigue: feeling so exhausted that it's hard to carry on with normal activities.



Fever: a high temperature (above 38°C) that might come and go. Fever can also be a sign of infection and **frequent infections**, or ones that are more severe or last longer, can also be a symptom.



Penelope's story

Penelope talks about her diagnosis of follicular lymphoma

I first realised something was wrong in March 2021. I am 74 and had been very active and generally well. I started to get strange cramps between my knee and hip, which were really painful at night. As well as the cramps, I had a pain that started in the middle of my back and moved round into my rib cage. I thought I must have caught a nerve in my spine and that the problem was actually to do with my back.

My left hip was also occasionally giving me pain, but I put off contacting the GP because I thought it wasn't urgent and that they would be too busy because of COVID. It never occurred to me that it might be something serious.

After about 10 days I was exhausted with the pain, so rang the surgery. I was given a telephone appointment a week later and the doctor suggested I see a physiotherapist the next day.

By the time I had this in person appointment, I was losing my balance and walking strangely. I also had a numb feeling down my back, and my legs and feet were going numb. I was told it would be a blue light emergency if I lost control of my bowel or bladder.

I had an MRI and CT scan, followed by a biopsy and PET scan. Within a week I received a telephone call saying I had grade 2, stage 4 follicular lymphoma. I was told I had a mass around my aorta which was compressing the nerve in my spine at the junction where it split and went down my legs and this was the reason I was experiencing the numbness.

I didn't research follicular lymphoma. I realised it was a complicated disease, and everything felt overwhelming, so I put my faith in my medical team. In truth, I don't remember much of the conversation, but I do recall being told they were planning to start

treatment with chemotherapy and steroids straight away. I clung on to that at the time and didn't ask many questions.

A diagnosis of cancer was a shock. My husband had an incidental finding of pre-cancerous cells several years previously and so in my mind I thought it would be me looking after my husband and not the other way round.

I had the diagnosis on a Friday and started the chemotherapy on the Monday. Steroids started a few days later and their effect was almost immediate. I had been in so much pain that the effect of the steroids felt like a miracle.

My consultant told me that if the treatment did not work, he had other things up his sleeve.

I didn't know what to expect with the treatment, but I found the chemotherapy difficult. I had a mixture of chemotherapy drugs and steroids as well as a monoclonal antibody (obinutuzumab) – all intravenously. I would go to the day treatment unit first thing in the morning and was usually the last patient to leave at the end of the day. Early on in my treatment I was thrashing around in the bed at night with tingling feet and hot flushes, not knowing where to put myself. Steroids made me hyper and then depressed and I found it very difficult to sleep.

The chemotherapy was for five months, so my life was punctuated by the three-weekly Mondays when I would return to face another session. I was given prophylactic anti virals (acyclovir) and anti fungals (fluconazole) and a stomach protector drug (omeprazole) to take daily during the gap in the three-weekly cycles of chemotherapy. Initially it was planned to give me prophylactic antibiotics, but as they brought me out in an itchy rash they were discontinued.

After the third round of chemo, I developed a pain in my groin, which is still causing me problems, especially when I stand up or walk.

I was worried that it may be indicating that the lymphoma had gone into my bone marrow. However, a CT scan showed that the lymphoma had reduced by 50%, which the nurse said was a wonderful result. This was reassuring and I started to feel confident that the treatment was working. My consultant had also told me that if this treatment did not work, he had other things up his sleeve, which was also comforting to know.

I have struggled with side effects. I have peripheral neuropathy (PN) in my hands and feet, which gives me a sensation like numbness or tingling. It is a really peculiar sensation during the day, but is far worse at night-time. Someone suggested I use a cream containing 1% menthol (which helps with itching). I often use it at night and find that it does help.

I was told that the hip/groin pain was a result of nerve damage caused by the compression of the nerves in my spine and that vincristine, one of the chemotherapy drugs, would be stopped for the last three sequences because nerve damage is a known side effect. I was worried that because the vincristine had been removed, my treatment would be less effective. I was reassured that it would not be disastrous, and that it was important to report side effects.

Before treatment started, a nurse had told me I would lose my hair. After nine weeks my hair was still there, albeit a little thinner. But after the fourth treatment my hair noticeably fell out. I was really upset by this, despite knowing it was likely to happen. I already had a wig that I had bought after the first treatment, but it wasn't a success.

My daughter suggested we look on the internet, where there were lots of sites, three of which I found particularly good. I ordered several wigs, which were posted to me and which I could post back if they weren't right for me.

I decided not to buy a real hair wig as I didn't expect to need it for very long. I also thought it would need a lot more care and attention than a synthetic wig. The wig I did buy was heat resistant, so I could style it how I wanted and it didn't cost a fortune. It can be itchy, but it is nice to have the option to put it on when going out.

I have used some complementary therapies to help with some of the side effects I experienced during treatment and continue to experience. I've had massages to help with the feelings in my legs. I found one lady who made a real difference. She seems to intuitively know which muscles feel tight and how to release the tension. I think it helps to talk in detail about where you're experiencing pain and not to be afraid of saying how the massage feels as you are having it. Because I have been struggling with my sleep, I have tried reflexology too.

I am blessed with a wonderful family and husband. My children are all adults now, but I have been fortunate that two of them live nearby. They have been an enormous support and do everything to keep me safe. My son is a doctor, so he has been invaluable in helping me understand my lymphoma and the treatment I am having.

A month after I completed chemotherapy I had a PET scan which thankfully showed I was in complete metabolic remission.

Research shows that if you continue with maintenance of the monoclonal antibody infusion treatment (in my case obinutuzumab) every eight weeks for two years you are more likely to remain in remission. I have had two maintenance treatments to date.

I have used some complementary therapies to help with some of the side effects I experienced during treatment and continue to experience.

COVID has made life very much more difficult. No visitors are allowed during chemotherapy. Treatment means I am immunosuppressed and have to be extra careful, which limits our lifestyle. I will be having a fourth vaccine in a couple of weeks time which I look forward to, as the previous three have not produced any antibodies.

About follicular lymphoma

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. About 2,200 people are diagnosed with it every year in the UK. It can develop at any age, but it is more common in those over 60.

Most people live with follicular lymphoma for many years. You might have periods when you feel well and don't need treatment, and other periods when your symptoms get worse and you do need treatment.

In most cases, there is no known cause for follicular lymphoma. Some genetic changes are common in follicular lymphoma, but scientists don't know what causes them. There is not normally any family history of follicular lymphoma.

COVID-19 drugs, trials and studies

COVID-19 treatments available

New antibody and antiviral treatments are available to people with COVID-19 who are at highest risk of becoming seriously ill. These medicines aim to stop COVID becoming severe and to prevent hospitalisation or serious illness. The treatments are available across the UK, although the process for how to access them varies slightly, depending on where you live. Check out our website (see top of page) for details specifically for England, Scotland, Wales or Northern Ireland. In most cases:

- You should have received a letter about accessing new treatments. If you think you are eligible, but have not received a letter contact your medical team, GP or call 119 for advice.
- NHS Test and Trace will send you a PCR test kit to keep at home. In some areas a lateral flow test is being used. Call 119 to request a test kit if you have not received one. If you have used your test, you should automatically receive a replacement.
- If you have symptoms, take a test as soon as possible, even if your symptoms are mild, as most treatments need to be started within 5 days.
- A positive test should trigger a phone call from a COVID-19 Medicines Delivery Unit. If you are not contacted within 24 hours of receiving a positive test result, contact your GP or call 111 and ask them to make an urgent referral.

The National COVID Cancer Antibody Survey

There's still time to sign up to have your COVID antibody levels tested and help scientists work out what level of antibodies offers 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 are being treated for cancer. This includes anyone with blood cancer on an active monitoring (watch and wait) treatment plan or on maintenance therapy.

Sign up at covidcancersurvey.uk

COVID-19 antiviral treatments research

The PANORAMIC trial aims to find out if new antiviral treatments like molnupiravir help those with COVID-19 get better quicker and without needing to be treated in hospital. The study is open to people aged 50 and over, or aged 18 and over with a health condition that puts them at high risk of getting seriously ill from COVID-19, who have tested positive for COVID-19, and have symptoms that started in the last 5 days. No face-to-face visits are required, you can take part from your home anywhere in the UK.

For more information and to sign up to the trial, visit: panoramictrial.org

Information on this page correct at 10 February 2022. Check our website for updates.

Top Tips: having chemo

We often see people sharing their experiences and tips for different aspects of living with and managing lymphoma, through our social media and peer support services. In our new 'Top Tips' series we share some of these ideas and suggestions with our *Lymphoma Matters* readers.

Being practical

Practical things to think about in preparation for having chemotherapy.

- Ask the hospital about whether free car parking is available for you or anyone taking you to your appointment.
- Take a notepad and pen (and a spare) to write down questions as you think of them. Or you could use the 'notes' on your phone. You can also list what you want to take with you next time.
- Your medical records if you have them.
- Lip balm.
- Face wipes/ hand sanitiser/ tissues.
- Face mask (COVID).
- Your glasses.
- Ear plugs and black out mask if you want a nap in peace.
- Small blanket.

Your hospital team might also give you a list of what to bring with you on the day.

Snacks and drinks

Refreshments are available at most hospitals, but you might want to take the following with you.

- Bottled water (freeze one so it is still chilled later in the day) or use an insulated reusable flask or drinks bottle.
- Concentrated squash.
- Small cartons of fruit juice (you may want to avoid anything too acidic).
- Fruit tea bags (and ask for just hot water).
- Sweet and savoury nibbles – nuts, biscuits, crisps. (Some people find plain crisps help if they feel nauseous).
- Pineapple fruit pot (also great frozen if your mouth is sore).
- A favourite cake to treat yourself.
- Chewing gum to keep your mouth moist.
- Boiled sweets or Queasy Drops.
- Ginger biscuits, ginger sweets, lemon sweets or ginger tea bags - as ginger may also help if you feel nauseous.



**Make up your 'chemo bag' in advance:
include small cartons of juice, plain crisps
(helped with my nausea), a pen & notepad,
and a fleecy blanket (even in summer).**

Vicky, in remission from DLBCL





Take good quality ear plugs and blackout mask (when you are an inpatient) as there is no such thing as silence and darkness in a hospital at night.

Mike, living with skin lymphoma



Clothing

- Something loose fitting, as a cannula/ PICC line can get in the way.
- Elasticated waists are good for when you nip to the loo.
- The temperature can change from chilly to warm, so layers and garments that you can easily put on and remove.
- Fleece blanket (even in summer) - can be comforting.
- Poncho, shawl, loose tracksuit, warm dressing gown with hood.
- Fluffy socks and/or slippers to feel comfy.
- Spare clothes in case needed, such as if you are sick.
- Something you feel good in.

Things to keep you occupied

Having treatment can take some time, and it may not always be possible to have someone with you on the day. The following are suggestions for things to keep you occupied while having your treatment.

- A good book, magazine, newspaper or e-reader (and charger!)
- iPad, iPod or MP3 player, tablet or smart phone (and don't forget the charger!)
- Headphones.
- Download a gallery of favourite photos, take a special photo as a bookmark.
- Puzzle books, crosswords, sudoku, word searches (and a pen or pencil).



Loose, comfy, layered clothing so you can add or remove layers according to your temperature.

Fiona, in remission from stage 4b Hodgkin lymphoma



This information comes from our Facebook user community. This is not intended to be medical advice and is not a replacement for advice from your medical team. If you are not sure what to do to prepare for your treatment, or what to take with you, always consult your medical team.

If you have any Top Tips to share you can email the magazine editor at publications@lymphoma-action.org.uk or join our closed Facebook support group.

Our community of volunteers is making a difference

We are very lucky to have a wonderful community of volunteers whose invaluable time, skills, expertise and care make such a difference to the work we do.

During the pandemic we needed to adapt our volunteer activity and without their support, we simply wouldn't be able to deliver many of our important services, raise awareness and reach people in need who are affected by lymphoma.

Whilst over the past 18 months we have had to pause some of our volunteer roles and recruitment, we have focussed on moving online and adapted our volunteer activity.

Our volunteers are now facilitating online support meetings, moderating our closed Facebook group, checking in with regular service users who do not access online support, attending virtual meetings and Live your Life workshops and socialising with other volunteers across the UK at our online meet ups. This is alongside our Buddies and Reader Panel whose roles have always been from home.

Everything that has been achieved through volunteering in 2021, as highlighted in our poster opposite, has been made possible by the generosity of our volunteers.

As always, **a huge thank you from everyone at Lymphoma Action.**

If you are interested in volunteering with Lymphoma Action, please take a look at our website for available opportunities, or get in contact with us to discuss volunteering in the future. Find out more at:

lymphoma-action.org.uk/Volunteering
or email:

volunteering@lymphoma-action.org.uk



Volunteering in 2021

A big thank you to all our volunteers for the time, passion, skills and commitment they give in helping us to inform, support and connect people affected by lymphoma.



3,598
volunteer
hours

683
volunteer
activities

338
number of
volunteers

97
new volunteer
enquiries

25
new
volunteers

1
new volunteer
role created -
check in and chat

218 online support meetings
facilitated by volunteers



3,318
people affected by
lymphoma have
been supported by
volunteers

40
publications and
webpages reviewed
by Reader Panel
volunteers

190
hours spent providing
insights and guidance
to support our work

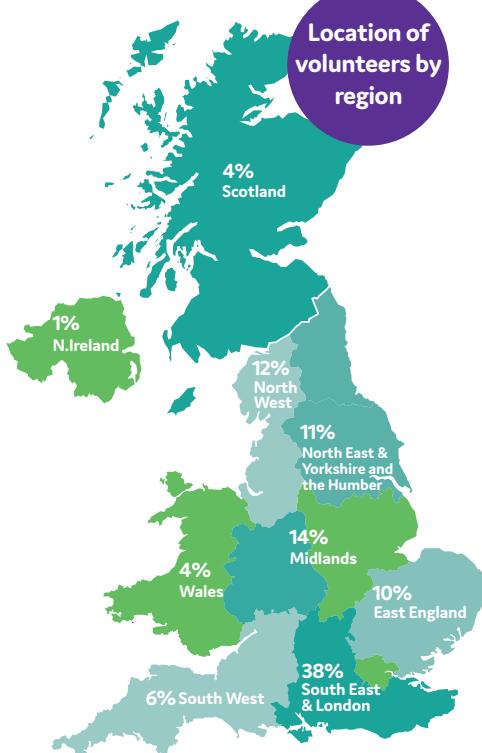


198
hours of
admin support
from home

'Volunteering has meant a lot to me personally as I feel I am using my skills and abilities to help others'

Lymphoma Action volunteer

Location of
volunteers by
region





My life has changed, my priorities have changed, I have changed.

Ian talks about his diagnosis of Hodgkin lymphoma, the challenges of treatment and the very positive effect it had on his life

Looking back eight years, I was 43 and working as a primary school teacher. I didn't think too much about my health until I started to experience a strange sensation of pressure in my throat, almost as if someone had their thumb on my windpipe.

I put off going to the doctor for as long as possible. When I did eventually get round to making an appointment, I was given a diagnosis which didn't feel right to me. I did nothing more about it, satisfied in the knowledge that I had at least been to the doctors. 'Job done, now just move on.'

However, a few weeks later I felt a lump on my neck near my collarbone, which raised significant alarm bells in my head. I went back to my GP and saw a different doctor who referred me to an ear, nose and throat (ENT) consultant. The lump, a lymph node

the size of a chicken's egg was removed, so that a biopsy could be carried out.

I was diagnosed with stage 3 Hodgkin lymphoma.

Hodgkin lymphoma? How was it that I could be diagnosed with what transpired to be the fifth most common cancer in the UK, but yet I'd never heard of it. How was that possible?

I was diagnosed with something I knew nothing about; it was a total bolt out of the blue.

My thoughts immediately turned to my children, who at the time were just 4, 5 and 7. I was a single parent, their mother and I having divorced a year or so earlier. We share custody, with them spending half the time with their mother and half with me.

I now needed to address some serious, but very pragmatic issues. Is this going to kill me? (It might). Will I be able to work? (If health allows, but sadly it didn't). How and what am I going to tell my children? (That was rather less straightforward).

In the end I decided to tell them I was poorly but made a conscious decision not to mention the 'C' word. My concern was that they would go to school, tell their friends 'daddy has cancer', only to be told 'my grandpa had cancer. He died!' I thought they could do without having to deal with that. So I decided to keep it to: 'I am poorly and I am going to be given medicine that will make me worse before it makes me better.' My 7-year-old daughter asked: 'What's the point of that? Doctors are supposed to make you better, not worse.'

Within four weeks of my diagnosis I was being treated with ABVD chemotherapy. I did extensive research into the potential side effects of my treatment and came to the conclusion that I would cope fine. Fatigue? I had young children, so thought I knew what that felt like, and I couldn't imagine sickness being a problem. In my mind I planned to carry on working and that life at home would carry on as before. Little did I know!

My ability to cope with the chemo was 'pathetic' (my consultant's very accurate description). My body simply couldn't cope. As well as the usual permanent nausea, heartburn, ulcers, and overwhelming pain all over my body, the delivery of the chemo caused enormous pain in my arm. As a solution to that particular issue, after an aborted attempt to have a PICC line inserted, I had a Hickman® line fitted. Whilst this relieved the pain in my arm and made the delivery of the chemo and other drugs easier,

it made cuddles with my children challenging, frequently uncomfortable and often impossible. My priority very quickly became the need to protect them and keep our little unit safe from the outside.

Being the father I wanted to be was becoming increasingly impossible and it broke my heart to think about what they were going through.

My consultant told me very early on in the process that I would often feel like I'd been 'hit by a truck'. She wasn't wrong! The simplest task made me breathless. At periods during my treatment cycle any kind of movement became practically impossible. I often couldn't get up the stairs, and felt utterly drained of all energy. My body couldn't cope with the sickness at all. Parenting became a task of Herculean proportions. I felt utterly useless.

I soon settled into a recognised pattern of sickness, fatigue, pain and uselessness. I felt really rough for about 7-9 days after chemo, and then slowly improved for a couple of days before having to go back for more treatment. My life became a well-rehearsed regimental cycle – hospital, chemo, feeling awful, repeat.

Halfway through my six months (twelve sessions) of treatment my salary was reduced by half as I had reached the limit of full sick pay. This created significant insurmountable financial difficulties. I couldn't afford to feed my children and I was twice faced with the very real prospect of eviction from my rented home.

I was put in a position where I was forced to return to work far sooner than my consultant, and more importantly my body, was ready for.

I tried to go back but felt far too ill; it was just impossible. My struggle eventually resulted in me being dismissed from my job as a primary school teacher because of my inability to perform to my usual standards, as a result of the chemo and its significant aftermath.

One of the things that really helped throughout the whole process was keeping a journal. I was never someone who kept a diary, but I thought it would be something to do during my chemo sessions, so I started a journal on day one of my treatment. Initially, it served as a record of what I did and how I felt, on a scale of 1-10. I found writing things down very cathartic, and would really recommend it. It was a good way of recording my thoughts, feelings – physical and mental – and, in the absence of having anyone at home, a way of being able to vent on the bad days.

I never regarded having cancer as a 'battle' or a 'fight', as people are often expected to. For me it was always a journey. To help with that I gave my cancer a name – Patrick. This was a journey Patrick and I would travel on together. We were inseparable. Patrick became an intrinsic and fundamental part of my life. One I was desperate to get rid of, but my companion nevertheless.

As someone who has suffered from severe depression and experienced overwhelming dark thoughts for decades, I can honestly say that my lymphoma experience has been an epiphany for me. My life has changed, my priorities have changed, I have changed. There are things I just don't worry about any more. Lymphoma had made me realise how much I have to live for, as a dad and now as a husband.

In many ways, bizarre as it may sound, having cancer was the best thing that ever happened to me. Patrick saved my life.

It's now 8 years since my diagnosis and I am in full remission. About two years ago, I decided to look back on my journal and it brought back all the feelings and experiences I'd had, many of which I had forgotten. I wasn't too sure what to do with them at first, but I decided to organise and structure my notes and a book grew from there. I took a term off work to dedicate my time to it, getting it finished and published. It took far longer than I anticipated but the result was my book - *The Adventures of me and Patrick: A Cancer Journey with a Difference*. I hope that the tales of my journey with Patrick offer an honest, insightful and humorous account of the reality of cancer from someone who has lived experience. My hope has always been that reading my book may be of some benefit to those who are on their own journey, or those supporting someone through the process, and for those suffering with mental health issues.



Ian and Patrick have a Twitter account, set up to try to raise awareness of issues faced by people with cancer, those on their cancer journey and those facing mental health issues - @MeandPatrick – and would be delighted if you would follow them.

The Adventures of me and Patrick: A Cancer Journey with a Difference by Ian Fry is available on Amazon.

Our podcast series

Lymphoma Voices is a series of podcasts (audio recordings) for people affected by lymphoma. In each podcast (see the list below), we are in conversation with an expert in their field, or someone with lived experience of lymphoma.

Understanding relapse in lymphoma

– Advanced Nurse Practitioner Charlotte Bloodworth on relapse in lymphoma and strategies for coping with relapse.

Support is the thing that helps you to cope

– Patron of Lymphoma Action, Lord Menzies Campbell, on his greatest achievements since his lymphoma diagnosis in 2002.

The role of the pathologist in a diagnosis of lymphoma

– Consultant Haematopathologist Bridget Wilkins on the role of pathology in the diagnosis and management of lymphoma.

Kicking on – Scotland 7s international rugby union player and Team GB member Robbie Fergusson on the impact his Hodgkin lymphoma had on his career.

Enhanced supportive care – Palliative Care Consultant Dr Dan Monnery on the principles of enhanced supportive care and the benefits of this approach for people with lymphoma.

The last surviving sperm in the facility – poet, author and illustrator Giles Andreae on his lymphoma and how it inspired him to write about love and happiness.



Being in the company of people – actor

Jamie Beamish on his experience of Hodgkin lymphoma, his stem cell transplant and the impact it had on his career.

Little rocks and lollipops – presenter

Emma Forbes on her experience of supporting her sister, while living overseas.

Looking to the future and the kindness of strangers – sisters Sarah Standing and Emma Forbes on Sarah's diagnosis of lymphoma and the emotional challenges of supporting a loved one.

Focusing on your emotional wellbeing –

Consultant Counselling Psychologist Angela Waing on emotional wellbeing and strategies to support positive mental wellbeing.

Why I find lymphoma so interesting –

Consultant Haematologist Dr Graham Collins on why he finds lymphoma so interesting.

The role of the GP in managing lymphoma

– Dr Sarah Jarvis talks about the role of the GP for people living with lymphoma.

Released on the first Friday of alternate months, find our podcasts at:
lymphoma-action.org.uk/LymphomaVoices



Fundraising in memory of someone special

Fundraising in memory of a loved one is a very special and meaningful way to remember them – honouring their life while also supporting people affected by lymphoma. Many people choose to set up JustGiving pages dedicated to their loved ones. These pages provide a simple and sensitive way to raise money online while remembering a loved one. Find out more at lymphoma-action.org.uk/donate-memory

Simran's family

In October 2021, Simran sadly passed away aged 26, due to post-transplant lymphoproliferative disorder (PTLD), a very rare form of lymphoma. Her family set up a JustGiving page shortly after she died and have raised an amazing £51,644 to support our work, with donations coming in from all over the world as a show of support to Simran's family.

Simran's family reflect on why they wanted to support Lymphoma Action in her memory. 'In February 2020, Sim got engaged to her partner Arun and, like every girl, she was planning her wedding to perfection. The proposal was magical, the wedding booked for July 2021. She was so excited to start the next stage in her life, from her dream wedding and honeymoon to having children.'

In early 2021, Sim developed excruciating back pain and weight loss and in April she was diagnosed with lymphoma. She started

treatment in May, initially having a course of immunotherapy before six rounds of chemotherapy. She was also told that she may be suitable for CAR T-cell therapy. It was looking as though there was light at the end of the tunnel, but unfortunately Sim's lymphoma was very aggressive. Sim died peacefully on 28 October 2021; she was the most courageous girl we know.

As a family we are determined to keep Simran's memory alive by telling everyone about her and her incredible strength, while raising awareness about lymphoma. We also want to support the charity who were a great source of information and support throughout Sim's treatment. Our promise to her is that for as long as we live, and with every beat of our hearts, she will never be forgotten. We love her so much, and for us, this is not the end, it is just the beginning.'

If you have been bereaved or affected by anything in this article, please call our helpline on **0808 808 5555**.

Live your Life

We know that it can take time to adjust after finishing treatment or being on active monitoring for lymphoma. That's why we offer our Live your Life workshops – to help you find your 'new normal' and live well, with and beyond lymphoma.

Live your Life virtual workshops

Our Live your Life virtual workshops are run via zoom from 10am-3pm. They are facilitated by trained volunteers with lived experience of lymphoma and supported by clinical nurse specialists. The workshops allow you to connect with others in a similar situation and we encourage discussion and interaction throughout the day. You are also welcome to bring a friend or family member for support.

Live your Life mini course

As well as the workshops we offer the Live your Life mini course. This is an on-demand, self-paced online course to help you take control of living with and beyond lymphoma. It consists of videos that cover the five modules of our Live your Life workshops. Find out more at lymphoma-action.org.uk/LYL

New companion workbook now available for people attending the course

Our new Live your Life workbook is packed with valuable information to help you understand your lymphoma and the emotional impact it has. It also covers exercise, diet and nutrition and practical aspects of living with and beyond lymphoma.



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 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 information about COVID-19, and wellbeing. Find out more at lymphoma-action.org.uk

Lymphoma Voices – our podcast series includes personal experiences and medical opinion. Find out more at lymphoma-action.org.uk/LymphomaVoices

Live your Life – virtual self-management workshops to help you improve your wellbeing after treatment or if you are on active monitoring. Find out more at lymphoma-action.org.uk/LYL



Bridges of Britain - Sunday 22 May 2022

We're delighted to be bringing back our Bridges of Britain walk.

This is a family-friendly event that you can take part in wherever you are in the UK. It's designed to be your walk, your way and this year we are running it as a virtual or in-person event.

To take part in your local area, you just have to complete a 7 mile walk, crossing at least one bridge. If you'd like to join us in London, we will be walking from Vauxhall to Tower Bridge, crossing 10 iconic bridges.

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