

Lymphoma
action 

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Inform | Support | Connect

Our impact in 2022

Lymphoma Action was established in 1986 and is the only UK national charity dedicated to lymphoma, which is the country's fifth most common cancer.

Our vision

Everyone affected by lymphoma will receive the best possible support, treatment and care.

Our mission

Through information, education, support and influence, we will make sure no one has to face lymphoma alone.

Our values

- **Focused** – we are dedicated to the needs of those affected by lymphoma
- **Empowering** – we build confidence to make change happen
- **Trusted** – we use our expertise to deliver quality services
- **Innovative** – we look to a better future for people affected by lymphoma
- **Collaborative** – we are inclusive and value our partnerships



I hugely appreciate all the help you are giving me. To say 'thank you' just doesn't cover the extent of your help!

Welcome

I am delighted to share with you some of the Lymphoma Action community's achievements in 2022

Whilst the year saw the effects of the COVID-19 pandemic ease for many people, we were mindful of providing a careful balance when it came to delivering our services and fundraising.

There were many highlights in 2022, including being able to support even more people through online peer support services, and delivering our health inequalities work. And thanks to your support, we raised £2m to develop our services further so that we can reach more people affected by lymphoma.

In the next year, over **20,000** people in the UK will be told that they have lymphoma. Despite huge advances in treatment and research, the need to support people living with a lymphoma diagnosis

remains unchanged. We're here to support people at every stage of their experience with lymphoma, as well as their families, friends and carers. You can read about what we hope to achieve in the coming years in our revised long-term strategy [available here](#).

As always, we cannot achieve our goals without the strong community of supporters, staff and volunteers who make this all possible. I would like to thank everyone who supported us in 2022.

Ropinder Gill
Chief Executive



Goal one – to create the highest quality information so people can understand their lymphoma

We sent over 75,000 copies of our *Lymphoma Matters* magazine to inform people about the latest developments in diagnosis and treatment, symptoms management and personal stories from people affected by lymphoma.

We produced two animations (*What is Lymphoma?* and *About Lymphoma Action*) to raise awareness about lymphoma as a condition, and the support we offer as a charity.

We revised 55 of our web pages, and over **1.2 million people** accessed our website to find out more about lymphoma, and the support available for anyone affected by the condition. We also continued to provide up-to-date COVID-19 information with over 63,000 page views on our website.

We revised six information booklets, and distributed 30,716 of our information books and sheets to ensure people have the most up to date information about lymphoma.



"I can't stress how incredibly helpful we found your book – it was literally messaged and emailed around friends and family."



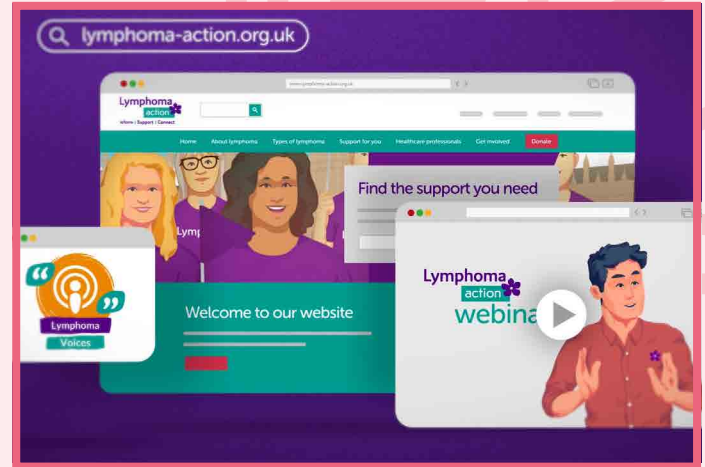
“Your web pages gave me the information to talk to my oncologist and more hope for what is ahead.”

We achieved PIF TICK accreditation, a quality mark to demonstrate our provision of trusted health and care information.



Seven live webinars covered a variety of topics and answered questions on everything from symptom and side effect management, employment rights and remission to the different roles within a healthcare team treating lymphoma.

Seven new *Lymphoma Voices* podcast episodes shared insights from medical experts and personal stories from people affected by lymphoma.



“All the webinar speakers were excellent. The doctors explained things clearly and the other two speakers both gave really illuminating talks.”



Goal two – to ensure that people affected by lymphoma can access the treatment and care that they need

497 healthcare professionals (HCPs) attended our two education events to better support their patients. After attending our *Lymphoma Management* course:

- **92%** said it will help ensure their patients are more informed and understand their condition.
- **99%** said they would recommend the course to a colleague.



“Lymphoma Management is a great course, allows you to keep up to date, great speakers, very good price and convenient after work.”

181 people attended our *‘Lymphoma Focus Day: Living with COVID’*, designed to help people following the easing of COVID-19 restrictions.

We took part in **28 Health Technology Assessments (HTAs) for NICE and the Scottish Medicines Consortium (SMC)** to represent the patient voice and support the availability of new treatments and drugs. This included treatments for DLBCL, rare lymphomas and COVID-19 treatments. We also appealed against the decision to not recommend Tafasitamab with lenalidomide for treating R/R DLBCL, which was upheld and the decision was taken back to NICE.

NICE

National Institute for
Health and Care Excellence

18 new lymphoma specific clinical trials were added to our *Lymphoma TrialsLink* database, with **69 open trials** listed for people searching for a UK-based clinical trial that might be suitable for their lymphoma subtype.

We collaborated with the Lymphoma Coalition to undertake a patient experience survey in the UK, with 500 people sharing insights about their treatment and care.

**LYMPHOMA
COALITION** 



Goal three – to ensure that people feel supported with and beyond lymphoma by others who understand what they are going through

We had 1,472 interactions with our Helpline Service via phone, email and Live Chat – with individuals feeding back that they felt grateful for the information and support provided; were able to safely express their emotions and could go on to develop their own plan of action.

1,664 attendees took part in **299 online support meetings** where they could share their experiences and receive support and information.

Six Special Focus meetings, with **145** people taking part in discussions covering specific topics of interest and concern for people affected by lymphoma.



“I joined the Facebook group to support my husband and the strength and support he’s received from you all has been amazing.”

1,084 people joined our closed Facebook support group to connect with others, taking the total group membership to **3,346**.

Our 256 volunteers provided 4,010 volunteering hours and supported 4,136 people affected by lymphoma. We also held our first *Volunteer Recognition Awards*, where 160 awards were presented.



“

“I absolutely love giving back to the organisation that has helped me so much.”

We made 40 successful Buddy links, giving people the opportunity to speak to someone who has been through a similar experience to them.

110 people attended our 13 Live your Life workshops and **86%** of people who registered for our **Live Your Life mini course** said it helped them to know what they can do to live well.

“

“I just would like to say a huge thank you to Lymphoma Action for organising the Live your Life workshop. I loved every single minute of it, it really was great!”



Cornita's story

My experience of lymphoma has brought all sorts of emotions out in me. I was diagnosed in 2021 but hadn't even heard of lymphoma. A lot of it didn't sink in at the time. All I could think about was 'How long will I live?' and 'What about my daughter?'

I went on to receive R-CVP chemotherapy and a PET scan at the end of treatment showed I was in remission. I feel I'm not yet out of the woods and my daughter worries a lot that the lymphoma will come back.

That is why I have found the Lymphoma Action Closed Facebook Group so valuable. It feels such a safe, warm and friendly environment where people can talk about their worries or concerns, pose questions, discuss topics and share triumphs. It really has helped me get through this experience.

I feel passionately that people should know more about lymphoma and I want to support others who are going through a similar experience to me. Being a part of this special community has really helped me to do that.



"I want to support others who are going through a similar experience to me."

Goal four – to be a voice for people affected by lymphoma in order to influence the decisions that affect them and raise awareness of lymphoma

We have developed a robust policy strategy led by a new, dedicated post to:

- represent people affected by lymphoma on a national policy platform and advocate for change.
- understand the health inequalities that can impact on the treatment and care of people living with blood cancer.
- strengthen the voice of people affected by lymphoma through collaboration with our partners, including *Cancer52*, *One Cancer Voice* and the *Blood Cancer Alliance (BCA)*.





As part of *One Cancer Voice*, **we asked the Government for clarity and commitment to improving cancer care and treatment** in its long term plans.

We chaired the BCA health inequalities roundtable to better understand the unmet needs of blood cancer patients from minority ethnic backgrounds, and make recommendations for change.

We represented people affected by lymphoma through attendance at the **Lymphoma Coalition Global Summit**, at industry partner meetings and at patient and charity forums.

We raised awareness about lymphoma through social media, radio interviews and the press at both a regional and national level by sharing people's experiences with lymphoma, and stories from supporters raising funds to support our work.

Goal five – to have the most effective resources so that we are sustainable and can deliver impactful services

Thanks to our wonderful supporters, we surpassed our annual income targets and raised £2,079,892, reflecting an increased appetite for events and community fundraising. This allowed us to spend £1.8m, over £332k more than in 2021.

We welcomed a new Chair of Trustees, along with new **members of our Board of Trustees.**

We supported our staff team and moved to new office premises, improving our hybrid working practises and ICT infrastructure to support this way of working.

We developed the ICT and Digital infrastructure required to support our new online support meetings and improve the functionality of our website, as well as investment in more effective cyber security frameworks and measures.

We continued capacity building through increased recruitment activity and investment in new roles.



Lyle's story

I was diagnosed with Hodgkin lymphoma at 19. Looking back, I never noticed any of the typical symptoms, such as losing weight or having night sweats. Without the lump I found in my neck, I wonder whether I would have noticed?

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

I was treated with four cycles of chemotherapy. At a mid-point scan, it looked as though the cancer had gone, so my treatment was changed to a less toxic regimen. Overall, I managed pretty well with the treatment.

Having lymphoma has massively changed my perspective on life. In the past I never thought about health or the importance of the help charities can make to people's lives.

I'd been fortunate that I hadn't needed any support before. But I realise that in most cases people need support through no fault of their own. That is why I feel so passionately about supporting Lymphoma Action, so that they can continue to help people like me and my family.



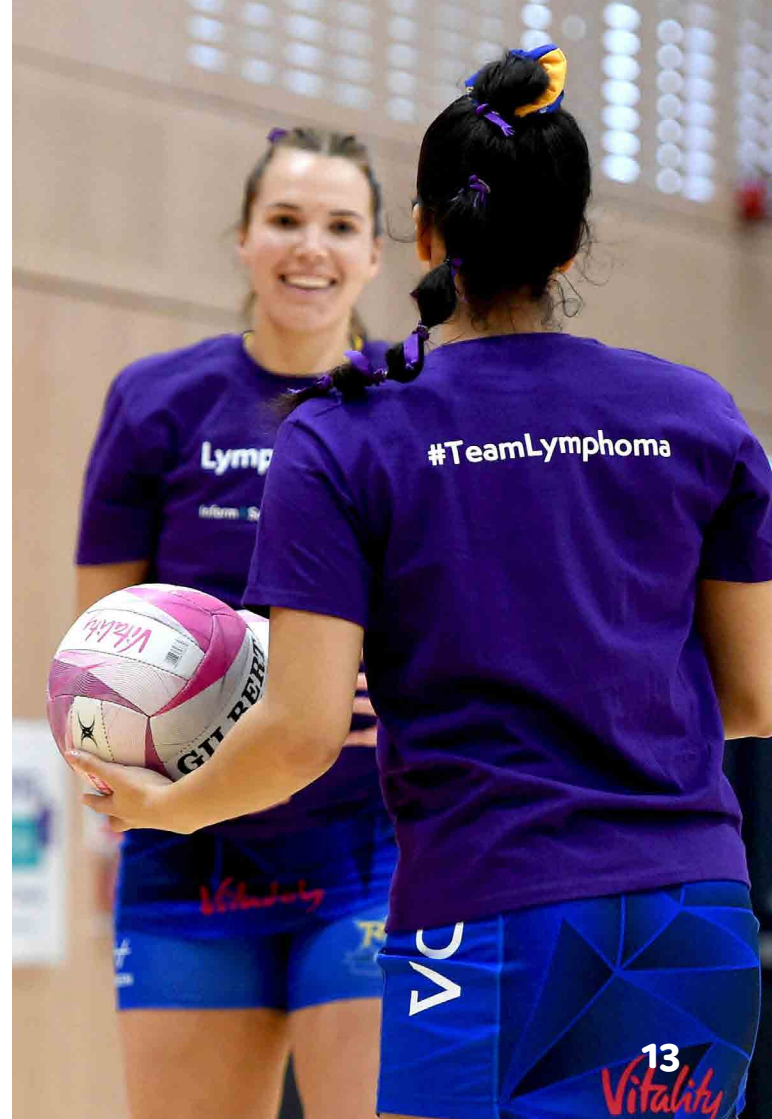
"I realise that in most cases, people need support through no fault of their own."

Looking ahead

In 2023, our aim is to continue to develop our services in line with the five goals in our strategy.

Some key focus areas for 2023

- Further develop our peer support services and our suite of new online support meetings.
- Continue to support and educate healthcare professionals, creating a new educational resource for nurses new to lymphoma.
- Build on our work around health inequalities and information accessibility.
- Scope and develop a prehabilitation project to provide more information and support to people before they start treatment.
- Develop our website to make it more effective for the 1 million visitors that access it each year.



**Thank you for your ongoing support and
commitment which makes our work possible.**

Together we can make sure no one faces lymphoma alone.

If you're affected by lymphoma, we are here for you:



Visit www.lymphoma-action.org.uk



Email information@lymphoma-action.org.uk



Helpline (freephone) 0808 808 5555 (Mon to Fri, 10am to 3pm)



Live Chat via our website (Mon to Fri, 10am to 3pm)

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