

Lymphoma
action 

Inform | Support | Connect



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Improving the lives of
people affected by lymphoma

Our impact in 2020

Lymphoma Action is a national charity, established in 1986, to provide high quality information, advice and support to people affected by lymphoma – the fifth most common cancer in the UK.

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 can't thank Lymphoma Action enough for their support – I know they are always there for me, and that makes such a difference.

Welcome

I am proud to share with you the difference you have helped us make for people affected by lymphoma in 2020. It was a difficult year for everyone, and COVID-19 had an especially significant impact on those living with a lymphoma. Thanks to your support, we were able to safeguard our services to provide vital information and support to those who needed us during a very challenging time.

Despite the challenges, we learnt how important it is to stay true to our values and focus on our purpose. Reminding ourselves of why we exist has helped us to respond to the needs of those we support. COVID-19 meant that we had to make many changes to the way we worked in 2020.

We already had a good infrastructure in place which meant that we could all work well from home and react to the ever changing circumstances around us. We also accelerated our digital development and upskilled staff and volunteers to ensure that we could continue to deliver services and raise funds.

We also learnt that working with others is key - throughout 2020 we collaborated with our many partners to deliver information webinars, hold joint fundraising events and advocate around the impact of COVID-19 on



people living with blood cancer, and on cancer treatments and services. By joining forces with other charities, we could pool our resources, engage with a wider audience and act as a stronger voice for people affected by lymphoma.

I never fail to be amazed by the kindness and generosity of our supporters, and the hard work and dedication from our staff and volunteers. Whilst the reflections in this report do focus on what was an extraordinary year, throughout it all our mission has remained the same – **to make sure no one has to face lymphoma alone.**

We are truly grateful to those who have continued to support us. On behalf of everyone at Lymphoma Action, and all the people we support, thank you.

Ropinder Gill
Chief Executive

Our strategy

Our aim is to be there for people affected by lymphoma – whether they have received a diagnosis themselves or are a friend, family member or carer. Lymphoma is the most common blood cancer in the UK and is a complex disease, with over **60 different types**. Information and support is vital to make sure the 20,000 people diagnosed every year live well with and beyond lymphoma.

Our strategy is to change how people live with lymphoma – helping them to find their new normal, to understand, adapt and manage so that they don't have to face lymphoma alone.

To achieve this, we have identified goals to work towards – first through our Theory of Change and then refined and guided by what people affected by lymphoma told us they needed and where we can make the most difference.

This report is structured around these strategic goals, highlighting some key achievements and showcasing the impact this work has had for people affected by lymphoma through stats, quotes and stories.

Our goals

1. Create the highest quality information so that people can understand their lymphoma
2. Ensure that people affected by lymphoma can access the treatment and care that they need
3. Ensure that people feel supported with and beyond lymphoma by others who understand what they are going through
4. Be a voice for people affected by lymphoma in order to influence the decisions that affect them and raise awareness of lymphoma
5. Have the most effective resources so that we are sustainable and can deliver impactful services



Create the highest quality information so that people can understand their lymphoma

Sent 60,275 copies of our Lymphoma Matters magazine to our supporters, updating them on the latest developments in lymphoma diagnosis and treatment and sharing personal stories from people affected by lymphoma.

Distributed 22,937 information books and sheets to help people understand their lymphoma, treatment and the support available.

Revised 29 webpages and 5 information booklets to ensure people have the most up-to-date, accurate information.



I can always rely on the information to be easy to understand and factual. This has been a huge support for me, and has made it easier to relay things to other people.



Launched Lymphoma Voices podcast

to provide accessible audio content; share insights from lymphoma experts more widely and share stories from people personally affected by lymphoma.

Over 2 million people accessed our website to have their lymphoma questions answered, receive reassurance and find out more about the impact of Covid-19 – web traffic increased by 24% from 2019.

Our 8 live webinars, viewed by over 5,000 people provided information and answers to important questions around lymphoma and COVID-19, shielding, vaccinations and physical and emotional wellbeing.

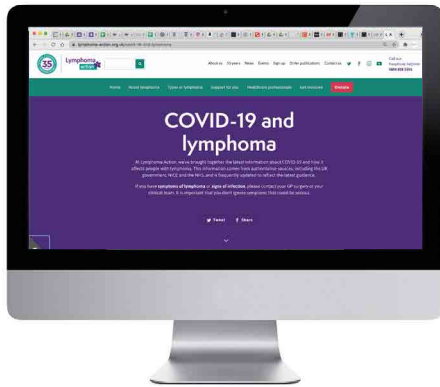


The COVID-19 webinar with a panel of experts was great, and another example of how Lymphoma Action provide up to date and trusted information, which is needed now more than ever.



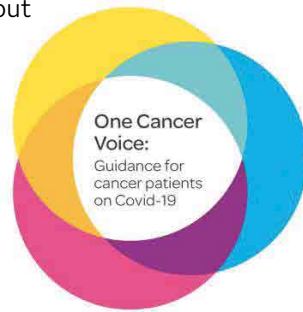
Spotlight on > COVID-19 and lymphoma information

People with blood cancer were classified as clinically extremely vulnerable to COVID-19 from the outset of the pandemic, and so depended on us for vital COVID-19 and lymphoma-related information throughout.

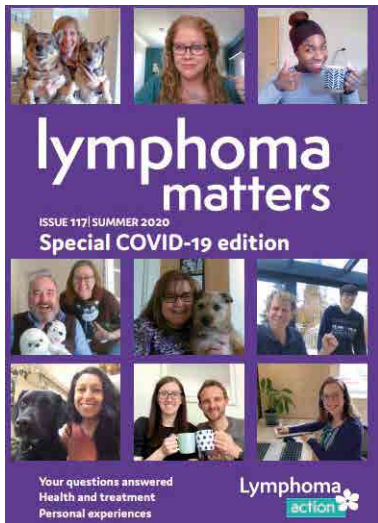


We created a new dedicated section on our website for **COVID-19 and lymphoma**, which covers a wide range of topics including shielding, vaccinations and personal stories and received a total of **163,423** views in 2020.

As part of the **One Cancer Voice** group of charities, we worked with NHS England to respond to frequently asked questions about COVID-19 from people living with cancer.



We created a **COVID-19 special edition** of our **Lymphoma Matters** magazine that provided answers from medical experts on common questions asked about COVID-19 and lymphoma, personal stories from people living with lymphoma during the pandemic and details on the information and support available to people affected by lymphoma.



Elsbeth's story



I was diagnosed with Hodgkin lymphoma in July 2019, and had finished my chemotherapy treatment just before the start of the UK lockdown due to COVID-19. Once the lockdown started I felt like I'd fallen off a cliff.

“Once the lockdown started I felt like I'd fallen off a cliff.”

I was so used to the routine of seeing my incredible cancer nurses and speaking to my consultant whenever I had questions, but now I couldn't even go the hospital if something was wrong through the fear of catching COVID-19.

This is where Lymphoma Action stepped in. When the twelve-week shielding period was announced for people like myself, I initially found the information a little ambiguous. However, I knew the first place that I could go to for clarification was to Lymphoma Action's website, and I knew that if I picked up the phone to their helpline that someone will be there to support me too.

“However, I knew the first place that I could go to for clarification was to Lymphoma Action's website.”

I can never thank Lymphoma Action enough for the help they have given me. I remember sitting in the doctor's room, nearly a year ago now, hearing the words 'you have cancer' and I was handed Lymphoma Action's book about Hodgkin lymphoma. From that day, the charity has been the most incredible support system and it continues to be – now more than ever.

“...the charity has been the most incredible support system and it continues to be.”

2

Ensure that people affected by lymphoma can access the treatment and care that they need

390 healthcare professionals (HCPs) attended our online education events to hear from expert speakers on the latest updates.

We supported HCPs with regular information and support around COVID-19 and lymphoma, thanks to the input of our Medical Advisory Panel (MAP).

Our *Lymphoma Management* course for specialist trainees and consultants had the most attendees to date:

- 83% said it will help ensure their patients are more informed and understand their condition
- 78% said it will help ensure their patients feel involved in managing their condition and having informed discussions.



The *Lymphoma Management* course was highly relevant, practical and all the speakers were excellent.

Commissioned and launched new research as part of the Blood Cancer Alliance, to identify challenges in access to new drugs and treatments for people with blood cancer and to make recommendations for change.

Represented the patient voice through 27 Health Technology Assessments (HTAs) and consultations.

This contributed to the availability of four new and innovative lymphoma treatments through NHS England and two funded by NHS Scotland.

Highest UK survey response to date to the Lymphoma Coalition Global Patient Survey which increased our understanding of the lymphoma experience and the impact of treatment and care to better inform our work.



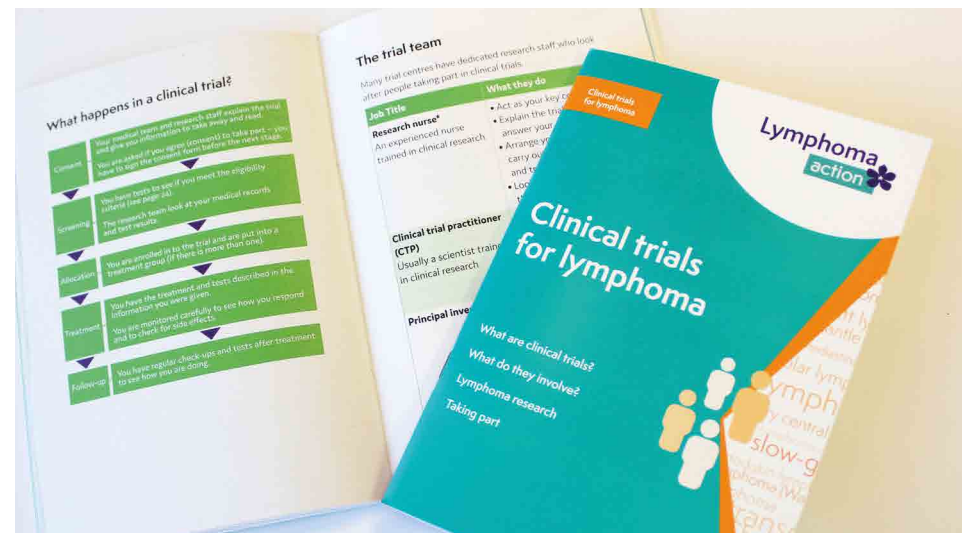
Spotlight on > Clinical trials for lymphoma

Our *Lymphoma TrialsLink* clinical trials information service aims to empower people to make informed decisions and choices about their treatment and care by finding trials and new treatments that may be suitable for their lymphoma subtype.



In 2020:

- The *Lymphoma TrialsLink* website page was accessed over **17,000** times.
- **17** new lymphoma specific clinical trials were added to our *Lymphoma TrialsLink* database.
- **162** trials were listed on the database in total (including those that were open, closed or trials with results).



3

Ensure that people feel supported with and beyond lymphoma by others who understand what they are going through

We had 2,055 interactions with our helpline service

where we provide information and support through phone, email and Live Chat – the most commonly discussed topics were COVID-19, risk of infection and symptoms of lymphoma.



The person on the Live Chat was lovely and helpful towards me. I'm so grateful you are here, I can't thank you enough.



1,520 people took part in 188 online support group meetings

across the country to feel informed, supported and connected at a time when face to face support meetings were not possible. New online support groups launched in Northern Ireland; for young people; and for family, friends and carers.



I hadn't heard of CLL before my diagnosis, but speaking to others in the online support group has certainly helped me in understanding my condition.

80% of requests received for our Buddy Service were successfully matched

with Buddies who provide peer support, and the opportunity for people to speak to someone who has been through a similar experience to them.

Live your Life self-management programme relaunched online for people completing lymphoma treatment, with 12 online workshops attended by 93 people – 90% said they would recommend the workshop to others.



The workshop covered lots of information, including self-monitoring which I wanted to hear about. The group discussion was really helpful and worked surprisingly well over Zoom.

1,500 people joined our new closed Facebook support group to connect with people affected by lymphoma all over the UK.

- 95% of members surveyed said it was meeting a need by helping others feel understood, and to feel supported during the pandemic.
- 83% said they feel more informed from joining the group and 75% said they feel more supported.



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



Russ's story

I was diagnosed with follicular lymphoma in March 2020 and was told that my lymphoma was treatable, but not curable. Because of COVID-19, I couldn't see anyone face to face to discuss my condition, but that is when I contacted Lymphoma Action.

They were incredibly helpful in sending me information about my lymphoma, and shortly after my partner Karen, and I joined one of their online support groups. They are a really friendly group, and have helped me to understand my lymphoma and ways to cope with it.



They are a really friendly group, and have helped me to understand my lymphoma.

Karen and I are also members of Lymphoma Action's closed Facebook support group which again has been a big support to the both of us. The online group and the Facebook page are there to pick me up, but they have also helped Karen too.



I think that people forget that our partners are going through a tough time too.

I think that people forget that our partners are going through a tough time too and also need support. Throughout this difficult time, it has been a comfort knowing that you are not alone.



Spotlight on > Volunteers

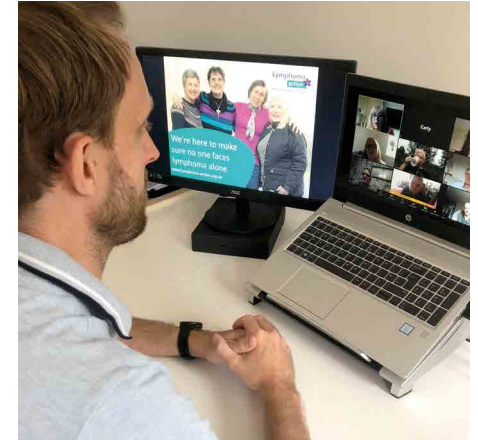
We are so grateful for the time, passion, skills and commitment given to us by our wonderful team of 318 volunteers.

It was a challenging year for volunteering due to COVID-19 restrictions and because many of our volunteers are affected by lymphoma themselves so had to shield throughout the pandemic. Our focus throughout was to make sure they felt supported and that we kept in regular contact.

Despite the challenges, our amazing volunteers:

- Donated **2,347 hours** of their time.
- Directly supported over **1,300 people** affected by lymphoma.

We were also able to develop some new volunteering opportunities to support our online activities. Our 'digital volunteers' helped us deliver additional online peer support to nearly **2,000 people** through online support meetings and our closed Facebook support group.



Raveen's story

I volunteer with Lymphoma Action to make a change in this world – I know first-hand how important their services are. I really appreciate how the charity values my own personal experience of lymphoma and enables me to use this to support others and I love the range of volunteer roles available.



4

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

During the COVID-19 pandemic it was vital that we put forward the issues that impacted on people affected by lymphoma to the policymakers who could address them.

- As part of the Blood Cancer Alliance, amongst other things, we wrote to the Government to express our concern about the shielding guidance that was issued to clinical extremely vulnerable patients during the second wave of COVID-19.
- Along with 24 other charities, we issued FAQs around COVID-19 and developed the *One Cancer Voice* 12-point plan for the restoration of cancer services impacted by the COVID-19 pandemic.
- One of 50 charities to write to the Prime Minister and the First Ministers of Scotland, Wales and Northern Ireland, asking them to give the NHS what it needs to protect cancer care services, minimise the impact of COVID-19 and uphold their ambitions to improve cancer survival.

We represented people affected by lymphoma by speaking at the Lymphoma Coalition global meeting, participating in the NCRI Lymphoma Research Group meeting and the NICE methods review forum and attending a number of advisory groups and forums.

We also continued to engage with our service users to inform our work through our Reader Panel and the introduction of a new Insights Panel.



For me, it's really therapeutic to talk openly about my situation. As a patient advocate, I share my own personal lymphoma story to help others.



Spotlight on > Raising awareness

As well as raising awareness about lymphoma through social media, radio interviews, and the press, we also wanted to make sure that people were aware of the importance of still contacting their GP if they had any health concerns during the COVID-19 pandemic.

With endorsement from Dr Sarah Jarvis, we supported the NHS *Help us, Help You* campaign to assure people of the safety of accessing primary care services, and keeping to routine appointments if they have a medical condition.

Lymphoma awareness

Visit your GP if you have any of these symptoms:



Losing weight but don't know why



Feeling worn out for no reason



A lump in your neck, armpit or groin



Itching all the time but don't know why



Drenched in sweat during the night

Dr Jarvis also supported our awareness campaign about the symptoms of lymphoma during **Blood Cancer Awareness Month**, by recording a series of short videos with us that were shared on social media.

We also supported the **#DistanceAware** campaign developed by NHS Wales to support people concerned about staying safe outside their homes to request ongoing social distancing. We produced a **distance aware badge** that was sent to over 1,300 people to wear to act as a reminder.



5

Have the most effective resources so that we are sustainable and can deliver impactful services

We maintained our financial stability by putting action plans in response to the risk of COVID-19, including emergency funding asks, access to government support, adapting existing fundraising activities and making significant savings on expenditure.

Our team quickly adapted to working from home to ensure that our essential support and information services could continue. Fortunately, we had already invested in a suite of new laptops with video conferencing technology. We also:

- Invested in a server-based telephone system so staff could receive calls directly to their laptops.
- Updated risk assessments, guidelines and policies to support safe and effective home working practices.
- Developed wellbeing support for staff including information and advice provision and increased staff communications.
- Supported the learning and development of staff, particularly around the digital delivery of services and fundraising initiatives.

We raised the income we needed to safeguard our services thanks to our wonderful supporters. In response to the social distancing measures brought about by COVID-19, we adapted our planned fundraising activities to ensure that, where possible, they could be delivered in a virtual format. We even introduced some new ideas along the way, including our virtual *Santa Run*, our first ever joint fundraising event, *Bridges of Britain*, with Leukaemia Care and the 20 for 20 fundraising challenge alongside the other Cancer52 charities.

While some of our planned focus on tracking impact had to be shifted due to COVID-19 priorities, the Inspiring Impact measuring up assessment showed **improvement in thirteen areas of our impact practice** since 2019.



I am in awe of the work that goes on behind the scenes at Lymphoma Action to support people affected by the condition.



Spotlight on > Diversity and Inclusion

Lymphoma Action is committed to ensuring that our workplace and our services are inclusive and representative of the communities that we are here to serve.

In 2020 we developed our **Diversity and Inclusion Framework**, linked to our values, to act as a roadmap for how we can meet this goal.

While this is an ongoing priority, in 2020 we:

- Implemented a new, more diverse Insights Panel to give us better insights into a wider cross section of the lymphoma community.
- Worked with our staff and trustees to build a shared understanding of where we are and commitment to what we want to achieve in making the organisation more diverse and inclusive.
- Focused on staff wellbeing as a means of supporting our teams through the pandemic in the most inclusive way.
- Worked to improve our governance, policies and procedures to support diversity and inclusion which included reviewing our staff and trustee recruitment practices.
- Started embedding diversity and inclusion in all our strategies and processes and began the process of trying to understand the impact of health inequalities on people affected by lymphoma.



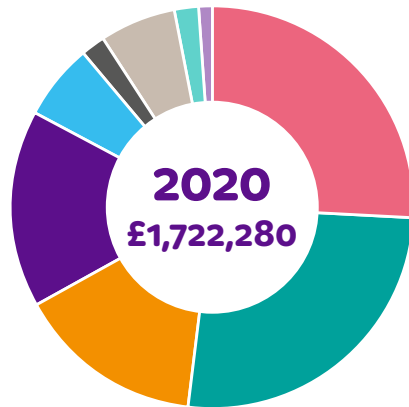
The COVID-19 pandemic highlighted many of the inequalities that exist around us – from differences in health outcomes to digital exclusion. We understand there is much more work for us to do to make sure our services are accessible and inclusive to everyone affected by lymphoma and this will remain a key focus in 2021 and beyond.

Income and expenditure

Income

Thanks to the generosity of our supporters and donors, in 2020 we raised a total of **£1,722,280** to fund our work.

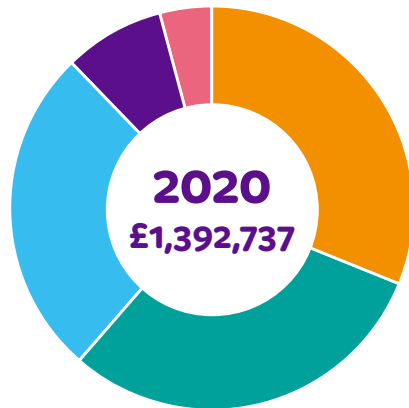
- Individual and community giving
- Trusts and companies
- Challenge events
- In memoriam and legacies
- Big Lottery Fund
- HMRC JRS Grant
- Gift Aid
- Education and training
- Merchandise



Expenditure*

Our expenditure in 2020 was **£1,392,737**, reflecting the need to control our costs due to the COVID-19 pandemic. To make sure we were able to respond to the needs of those we support, we continued to invest in our ICT and digital development projects so we could provide more of our services virtually.

- Support for people affected by lymphoma
- Publication production & distribution, information and raising awareness
- Costs of generating donations
- Education and training
- Costs of activities for generating funds



* All governance and support costs are allocated out across these activities proportionally.

Looking ahead

Whilst our priority for 2021 is to continue to provide support through a year that is still likely to be dominated by COVID-19, our mission and strategic goals remain the same. Throughout 2021 we will keep adapting our services to reflect the needs of people affected by lymphoma and we aim to increase our impact by making our information and support accessible and relevant to everyone.

In particular, we want to:

- Understand our different communities and what role digital services can play in supporting them, alongside traditional ways of providing support.
- Work to our strengths and identify any gaps in our service provision, as well as being responsive to the external environment.
- Better understand the barriers that may be holding people back from using our services or holding us back from engaging with them.
- Understand the health inequalities that may be preventing people from seeking further support, in order to improve health outcomes for all individuals, communities and groups affected by lymphoma.

Together we can make sure no one faces lymphoma alone.



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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