



Improving the lives of
people affected by lymphoma

Our impact in 2018

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer.

Established in 1986, we have been supporting people affected by lymphoma for over 30 years.

We inform with quality information, endorsed by medical experts.

We support at every step, providing reassurance, guidance and a listening ear.

We connect people going through a similar experience who can understand.

Our mission is simple – to make sure that no one has to face lymphoma alone.



Your charity doesn't just inform people and their families who are affected by lymphoma but brings people together, so they can share their worries and get support when they need it.

Welcome

I'm delighted to be reflecting back on our work with our first impact report.

Since joining the charity in August 2018 I have been so impressed both by the expertise and dedication of the staff and by the warmth and generosity of our supporters and volunteers. So it's great to be able to share with you the difference you have helped us make for people affected by lymphoma in 2018.

2018 was a year of change for Lymphoma Action. We launched our new website, embedded our new and exciting brand and further built our capacity in IT, digital and volunteering. However, we also faced some challenges – most significantly in our income generation – which meant that we had to make some efficiencies and revisit our strategy.

We have now have a clear ambition for the future that cuts across all our work – **to improve the quality of life for people affected by lymphoma and help them live the best life they can.**

So it's important that we continue to provide the services that people need, when they need them – no matter



what point of their lymphoma journey they are on. My vision is that Lymphoma Action can positively say 'this is the meaningful difference that we have made'.

We are here for the long-term, and our work is a joint effort between our staff, our volunteers and supporters whose generosity allows us to provide our services, develop and test new initiatives, and keep moving forward.

Thank you once again to all of those who have helped to make our work possible.

Together we can make sure no one has to face lymphoma alone.

Ropinder Gill
Chief Executive

Why our work matters

Lymphoma is the **most common blood cancer** in the UK, but is often hard to diagnose – with symptoms that can easily be mistaken for other conditions.

Lymphoma symptoms



Losing weight but don't know why



Feeling worn out for no reason



A lump in your neck, armpit or groin



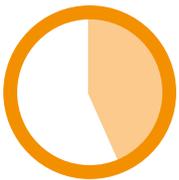
Itching all the time but don't know why



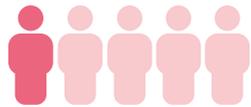
Drenched in sweat during the night

Lymphoma is a complex cancer, with **over 60 different forms or subtypes** – each with their varying presentations, diagnoses and treatment options. There is no known cause and despite its prevalence, it's still not widely recognised or understood.

Every **27 minutes** someone in the UK is diagnosed with lymphoma



1 in 5 young people diagnosed with cancer have lymphoma



Around **125,000** people are living with lymphoma in the UK



A lymphoma diagnosis changes lives.

We are proud of what we do to support people affected by lymphoma – but know that many more people could benefit from our services. Your support is essential to help us reach more people affected by lymphoma.

About this report

Our impact is the sustainable, long-term changes and improvements that people affected by lymphoma experience as a result of our work.

This is the first time we've set out to understand our impact in this way. We have always collected data about the use of our services and know that we reach thousands of people affected by lymphoma each year. We also seek regular feedback and people tell us that our services and support help them deal with everything a lymphoma diagnosis can bring.

What we are working on improving is our tracking of people's progress over time and our ability to identify the *specific ways* our services have improved their lives. This is not possible for all the work that we do, but in 2018 we used the Inspiring Impact Measuring up assessment tool to help us prioritise our areas of focus for the future.

We have structured this report around three strands of our work: Inform, Support and Connect. Each section starts by setting the scene about why this area of work matters, and then we highlight some of our key achievements and feedback. This is focused on the direct services and support we provide, as this is where we are able to better track and attribute the result.

However other areas of our work, like our campaigning, policy and influencing, also contribute to improvements for people affected by lymphoma. In 2018 we responded to a number of medical appraisals and consultations, sharing the views of people affected by lymphoma. This resulted most significantly in the decision to make CAR T-cell therapy available on the NHS in England, which is a ground-breaking treatment that offers new hope.

We hope this report gives you an insight into why we do what we do and the difference we're making to people affected by lymphoma, thanks to your support.



Inform

Why this matters



1 in 3

people diagnosed had never heard of lymphoma before¹



1 in 5

people reported that their GP knew nothing about lymphoma¹

Research suggests that having access to information about their condition helps people diagnosed with lymphoma feel more positive, more confident, more in control and less fearful.²



For me – being armed with information makes it easier to live with lymphoma.



It's so important to be empowered with up-to-date lymphoma information.

We provide trusted, up-to-date and evidence-based information in a variety of formats to help people understand their lymphoma.

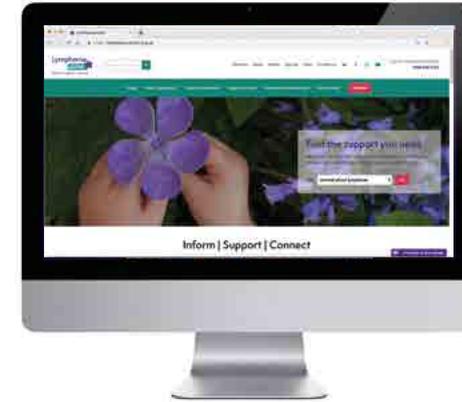
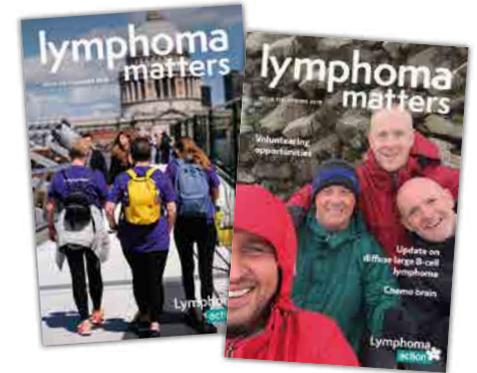
1. Lymphoma Association (2016) *Understanding lymphoma as a cancer – patients' experiences of lymphoma diagnosis, treatment, and aftercare.*
2. Lymphoma Coalition (2018) *Global Patient Survey on Lymphoma and CLL – UK.*

What we achieved in 2018:

We **distributed more than 70,000 written information resources** – booklets, information sheets and magazines.



The magazine has helped me with my diagnosis by bringing other people's stories and experiences to me.



We launched our **new website and other digital resources** to make it easier for people to find information relevant to them – including news and personal stories.



I found the information very useful and very easy to understand. I now feel I know and understand a lot more about my condition.

We created **two animated films to help explain lymphoma to children** in a reassuring and easy to understand way, one of which was shortlisted for the Charity Film Awards.



This [film] was amazing and worked really well for our kids...perfectly pitched.





Spotlight on: Active monitoring

Sometimes lymphoma doesn't require treatment straightaway. If it is slow growing and not causing immediate problems, there's no benefit to starting treatment before it is needed.

This is called **active monitoring** – or watch and wait – and involves both the person affected and the medical team looking out for any changes.

While this avoids unnecessary treatment and side effects, the uncertainty can be very stressful and it can be psychologically and emotionally challenging for people to accept that they're living with cancer and not undergoing treatment to get rid of it.



Watch and wait is counter-intuitive. There is no physical battle, but there is a psychological challenge.

Mark



Every little ache or pain, cough or cold makes you worry that things are about to go wrong.

Martine



People living with lymphoma on active monitoring are often not seen very regularly in clinics, but the mental strain of having a diagnosis and not being treated is massive.

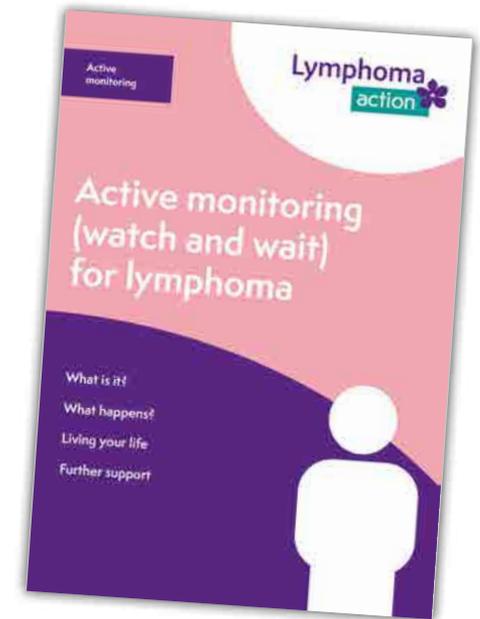
Charlotte Bloodworth,
Clinical Nurse Specialist,
Cardiff and the Vale
University Health Board



We identified from user feedback, calls to our helpline and reviewing other sources of information that there was a real need for more information and support.

In response in 2018 we:

- created a new booklet helping people to understand what to expect on active monitoring, the signs and symptoms to look out for and how to live a healthy life
- updated and expanded our web pages about the topic
- shared tips for how to cope on social media
- launched a series of films featuring people sharing their own experiences of active monitoring and what it has meant for them.



This is a really readable and useful booklet to keep referring back to...reassuring.



Support

Why this matters



1 in 2

people are given information about support at diagnosis³



79% of people were told about self-help groups – but only



1 in 3 is offered any other support³

A lymphoma diagnosis can impact on every aspect of a person's life and receiving support can help people cope through diagnosis, treatment, side effects and life beyond cancer.



We haven't really been offered any support at the hospital, just sort of sent on our way.



It's such a lovely feeling to walk into a room where hundreds of people just 'get it'.

We believe that people should be able to choose the type of support that suits them best, and we recognise friends, family and carers often need support too.

What we achieved in 2018:

Nearly 2,500 people used our helpline services – including telephone support, Live Chat and email support – meaning we could give them the all-important time and space to work through their feelings.



You've been very helpful – it's been good to talk to you. I feel a bit lighter knowing what you've told me.



Around 4,500 support group attendees benefited from peer support and a sense of community at our regular group meetings all across the UK.



I was scared and felt isolated. It was at that point I joined a support group – it's been a lifeline for me.



We held **three conferences** for people affected by lymphoma, connecting them to leading lymphoma expertise and to those going through a similar experience.



The best part of the day was meeting other people with the same experiences.





Spotlight on: Jeff's story

I had been feeling really ill for a couple of months. I was coughing and had night sweats, but it was the lack of energy that was so challenging.

A whole series of tests followed and I felt relieved when they found out what was wrong with me. I was diagnosed with mantle cell lymphoma in 2015.

My consultant handed me the Lymphoma Action *High-grade non-Hodgkin lymphoma* booklet and told me to read the sections on mantle cell lymphoma and stem cell transplants. The information helped me understand what would happen. It was absolutely accurate and reliable.



The information helped me understand what would happen.

The stem cell transplant was the lowest point for me. I was in hospital for 23 days. I lost six stone, I lost my hair, I felt weak and was struggling with fatigue. To start with, I shut myself off, not wanting to see anyone. Gradually my energy started to return little by little.



I found my local Lymphoma Action Support Group invaluable.

I found my local Lymphoma Action Support Group invaluable. We support each other and some of us meet to do circuit training too, which has helped me manage my fatigue.

I attended the Lymphoma Action National Conference which had the added bonus that I met someone with the same lymphoma as me! I also went to a Live your Life workshop, which helps people find their 'new normal' after treatment, and I can now accept when I have done too much.



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Jeff with his wife Anna

I still refer to the charity's website and *Lymphoma Matters* magazine to keep up-to-date with developments. I explain my relationship with Lymphoma Action as that of a trusted friend – someone who I can rely on to be open and honest with me about my condition and to support me in any way they can.



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Connect

Why this matters



1 in 5

people with lymphoma feel their family doesn't understand what they're going through⁴



1 in 3

people with lymphoma felt unable to connect with people following their diagnosis⁴

Being part of a community can make a huge difference when you're faced with the life-changing news of a lymphoma diagnosis. This is particularly important because many forms of lymphoma are long-term, and so are treated and managed differently from the majority of other cancers.



I know that many people who attend haven't spoken about their lymphoma-related problems to anyone.



Getting together with others who have the same type of lymphoma really helps....outsiders just don't understand.

We aim to connect people affected by lymphoma so they can learn from and support each other, and gain confidence to help others understand how they feel.

⁴ Based on data from Lymphoma Action's Live your Life evaluation report, November 2018.

What we achieved in 2018:

We created **54 new links** between our trained buddies and people who request to speak with someone with a similar experience. People become volunteer buddies because they want to share and give back and over **90% feel they have made a difference to others.**



I want to be able to give others hope and support, just as my buddy did for me.



921 people attended our Live Your Life workshops facilitated by people affected by lymphoma and offering practical advice and support.



This workshop provided me with space to reflect on how my life has changed and how I can look to the future with confidence and positivity.



We invested in our volunteer community, appointing our first-ever dedicated volunteering development manager and launching our volunteer experience survey. **87% of our volunteers are affected by lymphoma** and they say they **gain a sense of connection** through volunteering.



The satisfaction I get from helping others is so uplifting.





Spotlight on: Live your Life

We created our Live your Life programme in response to feedback that people felt isolated and confused after they had finished their lymphoma treatment or when on active monitoring.

Just 1% of people received information about support after treatment.⁵

Our interactive workshops offer practical information and support to empower people to adjust and live well with and beyond their lymphoma.

Facilitated by trained volunteers who have been affected by lymphoma, the sessions support attendees to connect with others who understand what they're going through and take away tips, tools and techniques to move on and live well.

We have been asking attendees to feed back how they feel one month, three months and six months after attending the workshop and our evidence indicates that their wellbeing and quality of life is improving over time.

Better able to cope

71% felt better able to cope with the diagnosis and treatment, rising to 92% six months later.

More in control

65% felt more in control of their life one month after the workshop, rising to 84% after six months.



It was so helpful focusing on setting and implementing personal goals.



72%
of attendees
reported
improvements
after the workshop,
increasing to
88%
after six months

Less alone

75% said they felt less alone as a result of the workshop, rising to 85% three months later.



The workshop has helped me feel less alone in my cancer journey.

More confident

75% felt more confident to speak to healthcare professionals one month after the workshop, rising to 88% six months later.



After finishing lymphoma treatment, I still felt like I had something to give. Training as a Live your Life facilitator allowed me to get my brain working again and I feel very privileged to run these workshops.



Penny, volunteer facilitator



The facilitator was inspiring in the way they'd learnt to live their life with lymphoma.



Live your Life was awarded a 2018 AbbVie Big Ideas for Better Health Award in the Supporting Self-Management and Self-Care category

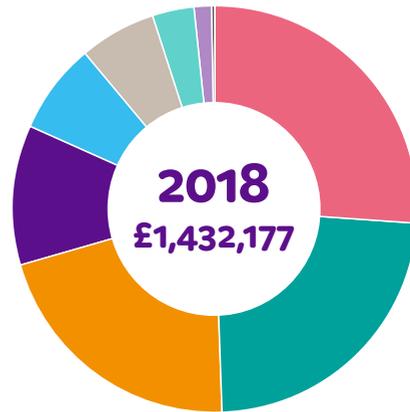
5. Lymphoma Association (2016) *Understanding lymphoma as a cancer – patients' experiences of lymphoma diagnosis, treatment, and aftercare.*

Income and expenditure

Income

Thanks to our generous supporters and donors, in 2018 we raised a total of **£1,432,177** to fund our work.

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



Expenditure

Our expenditure in 2018 was **£1,919,191**, reflecting our investment in development and diversifying our activities. Our ICT and infrastructure projects were covered through designated funds from a generous legacy payment.

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



Looking ahead

In 2018 we used a Theory of Change framework to set out our overall aim, which is supported by a number of goals which will be our focus while we work on our longer term strategy:

- 1. Create the highest quality information that people need so that they can understand their lymphoma.**
- 2. Ensure that people affected by lymphoma can have access to the right treatment and holistic care.**
- 3. Ensure that people feel supported throughout their journey with and beyond lymphoma by others who understand what they are going through.**
- 4. Be a voice for people affected by lymphoma so that they can be heard by decision and policy makers; influence decisions that affect them and raise awareness of their cancer.**
- 5. Have the most effective resources in terms of our systems, processes, workforce and income so that we are financially sustainable and able to demonstrably deliver impactful services.**



We will be seeking lots of feedback and insights from our audience groups and look forward to working even more closely with people affected by lymphoma so we can respond to the changing needs of the people that we are here to serve.

We know that collecting information to help us understand, measure and learn from our impact will help us be more effective and efficient – and therefore able to support more people affected by lymphoma. So we want to make impact a key pillar of our work going forward.



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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Inform | Support | Connect