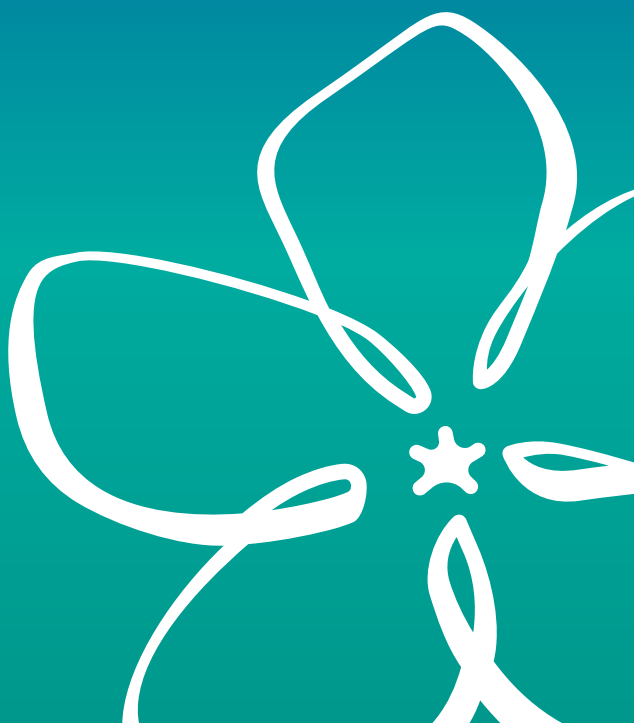
Lymphoma action

A better future for everyone affected by lymphoma

Our strategy for 2026–2029



Being told you have cancer is a life changing event and, every year, more than 18,000 people in the UK are told they have lymphoma - it's the most common form of blood cancer.

For forty years we have been ensuring that no one has to face lymphoma alone. We work tirelessly alongside our community, supporters, and partner organisations so that everyone affected by lymphoma receives the best possible information, support and care.

This means being able to talk to someone who understands, having a sense of belonging, and knowing that there are people fighting your corner and influencing the decisions that affect you. It also means reliable information, so that people understand lymphoma and are better able to manage their health.

> *"On my hardest days I've been able to reach out to people who have walked my path and give me encouragement and advice. It has allowed me to be part of a wonderful, kind community and I've never faced judgement here or worried about posting a question.*

This strategy outlines our ambitions for the next three years. We are a dynamic organisation, trusted by healthcare professionals, with our community at the heart of everything we do.

More than a quarter of people wait more than six months after noticing symptoms to get medical help

That is despite technology giving people a wealth of information at the click of a button. The NHS has ambitious plans for health and cancer services, with more use of technology and community healthcare, but it is a system under immense strain which makes realising these ambitious goals a daunting task. While lymphoma treatment has improved, over a fifth of people wait a further **6 months or more for a lymphoma diagnosis,** even after seeking help.

People with lymphoma face many challenges including widening inequalities, systemic barriers to getting referrals and all the psychological impacts that come with a cancer diagnosis. **Lymphoma is a complex cancer, with over 60 different subtypes.** There is no screening or test for lymphoma. If there is not an obvious lump, many people experience vague symptoms that are frequently confused for other conditions.

For some types of lymphoma, there is no immediate treatment, so people know they have cancer but have to wait until their symptoms worsen which leads to confusion, uncertainty and feeling unsupported. Many people with low-grade non-Hodgkin lymphoma live with it like a long-term condition, as over time it relapses and they need several different treatments over the course of their illness.

The emotional and practical challenges, such as balancing work or family responsibilities, are highlighted by our community time and time again. Carers are often overlooked, putting their own needs after those of loved ones.

> ***Over nine months, despite numerous GP and dermatology appointments, countless tests, and trialling various treatments, no one could explain the worsening itch. Sleepless nights became the norm, and the uncertainty was exhausting.***

> ***Active monitoring is counter-intuitive: I have cancer, but it's not being treated. There is no physical battle, but there is a psychological challenge.***

Our job is to do whatever we can to empower and support people with the best quality information and services they need. We work with experts and with our community to inform, support, connect and advocate on their behalf.

We are there at every step of the way for people diagnosed with lymphoma and their family, friends and carers. We have ambitious plans to address the challenges our community faces, supporting developments that will improve diagnosis, treatment and care in the NHS and pushing for better, kinder and more effective therapies.

We are continuously improving our information and support so that people get services that are tailored to their specific needs. And we want to do bigger and bolder campaigns so that more people recognise the symptoms of lymphoma and know where to get support.

All of this is underpinned by the generosity of our community. Thanks to their ongoing support and commitment, we are looking ahead with ambition and hope.

> ***I think it is very easy to feel overwhelmed...with little control of anything that is happening to you, so when I came across the concept of prehabilitation on Lymphoma Action's Preparing for Treatment Service, I was glad to have found something that was actually in my control.***

This strategy is grounded in what people affected by lymphoma have told us matters most including through the Lymphoma Coalition patient surveys. Key groups such as our Medical Advisory Panel, Insights Panel and Reader Panel also play an important role in ensuring our work is shaped by real life perspectives and experiences.

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

We work to a clear set of values in everything we do.

- **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.

Our goals

People **understand lymphoma** and are able to better manage their health

- Provide clear, quality and trusted information about lymphoma, developed with experts and shaped by the experiences of our community.
- Improve the accessibility of our information, our range of formats and how we use technology to meet the needs of as many people as possible.
- Develop new resources which empower our community and respond to their unique needs.

People affected by lymphoma have **improved wellbeing** and emotional resilience

- Reach more healthcare professionals with the support they need so people affected by lymphoma get the right care and support from the start.
- Further develop services which give tailored support at each stage of the lymphoma experience.
- Provide services which support the emotional wellbeing of people diagnosed with lymphoma and those close to them.

“Lymphoma Action has been the best source of information and support since I was diagnosed in June 2022. I’ve used the information links for a whole range of items about my lymphoma and its treatment and I’ve also given links to friends and family to help them understand.

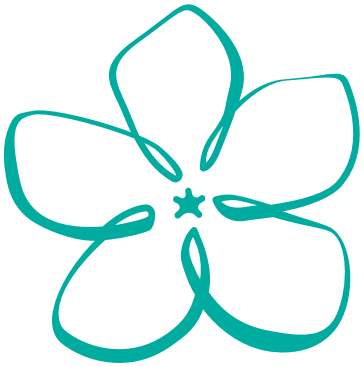
People affected by lymphoma experience a strong **sense of community** and belonging

- Foster a welcoming, inclusive community where people affected by lymphoma feel seen, heard and connected to us.
- Create safe spaces where people can share experiences, build connections and support one another.
- Make volunteering accessible and rewarding, recognising the vital role volunteers play in strengthening our impact.

People affected by lymphoma know who we are and contribute to our **collective voice**

- Be a positive voice for change and represent people affected by lymphoma in the conversations that shape their care.
- Support developments in the diagnosis, treatment and care of lymphoma and respond effectively to national priorities.
- Increase our ability to raise awareness of lymphoma, its symptoms and the work we do through bold and ambitious campaigns.

“I just wanted to say how useful this charity is. My partner, who’s 21, has just gone into remission after having stage 2 lymphoma in her neck and chest. If it wasn’t for your charity and the awareness you guys spread, I doubt either of us would have picked up on it!



Mez' story

I was diagnosed with diffuse large B-cell lymphoma in 2022. It was a crazy time back then, because we were in COVID lockdown and trying to get access to a GP and any kind of scans and treatments was almost impossible.

I could see my health deteriorating rapidly and it got to the point where by December 2021, my health was so bad that I couldn't even stand. I had stomach pains, I had severe sciatic nerve pain, I was short of breath, and I couldn't focus. I remember turning to my wife and saying 'I just can't live like this.'

I had private healthcare at the time and chose to access their services. Within two weeks they said they suspected non-Hodgkin lymphoma. I had a biopsy a week later and it was confirmed. My world came crashing down that day. My life didn't flash before my eyes - but there was a realisation of what had happened and what that might mean for my wife, my family, my kids.

Once I'd had that emotional reaction, I tried to tackle my cancer diagnosis like a project. I wanted to understand what I was dealing with. What does having lymphoma mean? If I'm going to go through chemotherapy, I want to know all about chemotherapy.

I found the Lymphoma Action website and it quickly became my go-to place to educate myself about this type of cancer and what it might mean. It was so helpful for me to know what to expect, so I could prepare myself physically and mentally. Now I live every day like a blessing.

I'm grateful to still be here. I feel like my calling now is to help others. Because even though it's different for everybody, it is better to be armed with information from trusted sources and connected to people who have gone through it than to face it alone.

Our strategy depends on us having the right people, systems and financial resilience to make the most impact.

We will fundraise ethically and effectively to support the work of the Charity and sustain our development. We will make sure we have robust governance to advance our goals. We will also gather greater insights from our community and rigorously track progress against our goals, reporting through our Annual Reports and Impact Reports.

Our success measures will include development milestones for our new services (such as Preparing for Treatment), for our website so information is easier to find, for expanded peer support, bigger awareness campaigns, and new resources and patient empowerment tools amongst others.

We will continually review how we measure and communicate the impact of this strategy as we embark on a journey to grow, innovate and make a greater difference for everyone affected by lymphoma.

> ***"I took part in the Bridges of London walk for the challenge, and the sense of achievement with the LA team and the other walkers.***

Lymphoma action

We are so grateful to everyone in our lymphoma community - whether you use our services, are part of our staff team, volunteer your time and expertise or raise the vital funds we need to continue our work.

Together, we can make sure no one faces lymphoma alone.

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

www.lymphoma-action.org.uk

information@lymphoma-action.org.uk

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

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

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