



## Our strategy for 2020 – 2025

### Changing how people live with lymphoma

# Introduction

**This document sets out our vision, mission, values and goals – what we want to achieve for people affected by lymphoma.**

It also highlights some overarching themes for our work and areas of focus to help us achieve our goals and be as effective as we can be. It sets out our direction for the longer-term, which we want to keep flexible, simple and most importantly, with those that we are here to help at its heart.

Not only does this strategy build on the foundations laid over 30 years ago by the volunteers who set up Lymphoma Action, it also plays to our strengths and helps us be prepared for what the future brings – both the challenges and the opportunities, including a health service that is changing and may look dramatically different in years to come.

People affected by lymphoma face all the challenges that come with being diagnosed with cancer – but through our expert focus on what they need, we hope 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.

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

Our vision is that everyone affected by lymphoma will receive the best possible support, treatment and care.

Our mission is that through information, education, support and influence, we will make sure that no one has to face lymphoma alone.

Our values underpin our work:

**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

# Context



In the next year almost **20,000 people** in the UK will be told that they have lymphoma.

**To deliver our strategy and what we want to achieve for people affected by lymphoma, it's important that we reflect on the environment in which we operate and the realities of a lymphoma diagnosis.**

## National priorities

Significant progress has been made nationally for people diagnosed with cancer and survival rates continue to improve – however a growing and ageing population means incidence continues to rise. There are a number of issues that need to be addressed at a national level to deal with this challenge, as set out in the [One Cancer Voice manifesto](#). These include having the right staff in place in the NHS; diagnosis that is quick and effective; giving patients access to the right treatment and post treatment support; and preserving the UK's status as a world leader in cancer research.

**We are committed to working together with the cancer community to influence and shape the cancer agenda to make sure that people are not just surviving cancer, but living well too.**

# Lymphoma matters

Better treatment will help many more people with lymphoma to survive longer than ever before – the five year survival rate has increased by nearly a third since the '70s and treatment options continue to expand all the time.

However alongside the promise of newer therapies, we must also ensure a focus on developing better, gentler treatment options and on quicker access to treatment and care. We know lymphoma symptoms can be vague and difficult to diagnose and the sheer number of subtypes mean a diverse range of patient experiences and that those with rarer lymphomas can feel less supported.

The physical, emotional and financial effects of lymphoma and its treatment can be debilitating, but this can often be underestimated, as lymphoma is generally presented as a cancer with a good outcome. There is a need to support people so that they feel better able to navigate the system and deal with the psychological toll of a lymphoma diagnosis and the longer term implications of living on active monitoring or with side effects.

**As the population affected by lymphoma grows, our ambition is to continue to be the go-to place to help people live well with and beyond lymphoma and to amplify the voices of those affected so that we can advocate together for better treatment, care and outcomes.**



# How we developed our strategy

In 2018 we started with a Theory of Change framework to set out our overall aim for people affected by lymphoma and a number of goals that would enable us to achieve this. In 2019 we combined this with desk research, needs analysis and a consultation with people affected by lymphoma, healthcare professionals, staff and volunteers to make sure that these goals reflected what people need and where we could make the most difference.

**Our strategy is underpinned by several interconnected themes which sit across all of our organisational goals. These are:**

- Increasing both our reach and impact – whilst understanding that everyone has individual needs depending on what stage they are at with their lymphoma.
- Strengthening our core service delivery – including identifying and addressing gaps in our provision.
- Playing to our strengths and USP as the authority and 'go-to' charity for lymphoma patients and focusing on that specialist provision.
- Understanding our different target 'communities' and what role digital services can play in supporting them; scoping and researching what they need and being realistic about how we can reach them.
- Understanding the longer-term picture and being responsive to the external environment in order to better position our services for the future needs of people affected by lymphoma.

# Our goals



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



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



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



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



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**

## **Why it matters:**

We know that people affected by lymphoma want to be informed about diagnosis, treatment and side-effects and that different people want this information at different times, or in different formats.

Research shows that having access to information helps people feel more positive, more confident, more in control and less fearful.



**'Being armed with information makes it easier to live with lymphoma'**

**'Glad to have this information available to help us understand the situation and treatments available'**





## What we will do:

- ★ Develop more detailed and niche information to cover more of what people need
- ★ Better understand our information reach into communities and their specific experiences, identifying gaps and areas of need to increase our impact
- ★ Strengthen and build our channels to distribute information, understanding specific audiences better, and using consultation, collaboration and technology to increase our impact



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

## **Why it matters:**

Access to the most effective new treatments is especially vital as lymphoma is a complex condition and often treated differently to other cancers. Some types of lymphoma relapse and require a number of rounds of treatment over many years. Holistic support during and after cancer treatment has been shown to improve quality of life on a psychological and physical level.



**'It's good to know that there are more treatments available should I relapse again'**

**'Your information has prepared me to discuss my concerns with my doctors'**



## What we will do:

- ★ Help identify those treatment priorities, quality of life issues and behaviours which would make the biggest difference in terms of better access to treatment and care
- ★ Develop a range of initiatives and educational services for healthcare professionals to support them in their diagnosis and treatment for people with lymphoma
- ★ Give people affected by lymphoma the tools, resources and confidence to have more effective communications with their healthcare professionals



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

## **Why it matters:**

Receiving the right support can help people cope through diagnosis, treatment, side effects and life beyond cancer. Being part of a community can make a huge difference and this is particularly important because many forms of lymphoma are long-term, requiring ongoing emotional, psychological and peer support.



**'Getting together with others who have the same type of lymphoma really helps'**

**'Meeting others who know how you feel and can relate to you when you want to talk can help you face further challenges in the future'**



## What we will do:

- ★ Continue to build resilient communities of people who can support each other in person and/or through digital means
- ★ Build a large volunteering community that increases the reach and breadth of our work in supporting people affected by lymphoma
- ★ Increase the impact of our helpline and educational services to support people to live well with and beyond their lymphoma, scoping additional needs across the patient pathway



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

## **Why it matters:**

Lymphoma is the UK's fifth most common cancer, but it is not well known and is notoriously hard to diagnose – people often tell us that their symptoms were mistaken for other conditions and so it is important that we continue to raise awareness. Involving people affected by lymphoma in research and policy ensures that their needs remain the focus of decisions.



**'I want my experiences to be positive, and to be able to influence other people and treatments'**

**'Knowing that mine is not a lone voice makes me more hopeful'**



Tell us what you think

## What we will do:

- ★ Collaborate with a broad spectrum of partners to amplify the voice of people affected by lymphoma
- ★ Develop our policy strategy to strengthen the voice of people affected by lymphoma on a national platform
- ★ Continue to strengthen our engagement with people affected by lymphoma to increase the quality and impact of our work
- ★ Develop communications and campaigns to deliver our message to a wide and diverse audience



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

## **Why it matters:**

We need to be a flexible, effective and sustainable organisation to adapt to challenges, make the most of opportunities and to ensure that we can support more people affected by lymphoma. The success of our strategy relies on the right staff, volunteers, partners, funding and infrastructure working together.



**'Volunteering has enriched my life as I hadn't realised until I did it, how much of a buzz I get from talking to others about the work of Lymphoma Action'**

**'It is rewarding to have a positive impact on the lives of those affected by lymphoma'**





## What we will do:

- ★ Invest in our people to build capacity, deliver quality services and be the most effective that we can be
- ★ Seek opportunities to collaborate with other blood cancer charities which will help us meet our aims better
- ★ Be financially strong and strategically resilient for longer-term sustainability
- ★ Develop our infrastructure, ICT and digital capabilities aligned to our goals

## Driving impact and quality

Impact is the long term change we enable for the people we are here to support. We have identified a focus on impact as a key pillar of our work going forward, as it will ultimately help us improve our services for people affected by lymphoma.

In 2018 we used the Inspiring Impact assessment tool to get a snapshot of our impact practice and areas to prioritise and we repeated this exercise in 2019 which showed improvements in a number of areas and confirmed our priorities for 2020 and beyond:

- Develop a cross organisational plan which sets out how and when we collect evidence and by whom this is done.
- Build more effective feedback and follow up processes with a wider range of beneficiaries.
- Better understand external and other factors that influence outcomes for beneficiaries along the patient pathway.
- Share more of our work and our findings – both internally and externally – to promote transparency and learning.

**‘I can never thank Lymphoma Action enough for the help they have given me’**

# Valuing people and learning



We recognise the importance of people in delivering this strategy and improving our impact and so we have been working on our People Strategy, Volunteering Strategy and Learning Strategy as key building blocks for the charity moving forwards.

Updating our values was the first step in changing our culture and ways of working to improve our ability to deliver our mission for people affected by lymphoma.

Our increased focus on learning and development is helping to foster innovation and new ideas to propel the organisation forward. We understand that embedding organisational change takes time, so we are committed to working towards this and ensuring that we invest in our people on an ongoing basis so we are as effective as we can be.

## We need you!

We can't achieve our goals on our own – your ongoing support is invaluable.

Whether you work for us, volunteer your time and expertise, fundraise, campaign, support our events, promote our services or work in partnership we are very grateful and appreciate your continued passion and commitment.





**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](http://www.lymphoma-action.org.uk)**
-  **Email [information@lymphoma-action.org.uk](mailto: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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