

Lymphoma is the **fifth** most common cancer in the UK

Every 28 minutes someone is diagnosed with lymphoma*. Despite this, people with lymphoma remain under-represented in policy, diagnostics, treatment and post-treatment support. We represent the people affected by lymphoma, who tell us that they feel overlooked and under-resourced. We need your help to improve their lives.



HELP US *give people affected by lymphoma a voice*

HELP US *to highlight the issues they face*

HELP US *to inform and inspire change*

We are the only UK charity dedicated to supporting people affected by lymphoma. There are more than 60 different subtypes of lymphoma and we are uniquely positioned to recognise the differing needs that each type of lymphoma presents.

*Includes Hodgkin lymphoma, non-Hodgkin lymphoma and CLL

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Lymphoma
association

What is lymphoma?

Lymphoma is a complex disease. It can be difficult to diagnose and has a wide range of treatment options.

There are two main types: Hodgkin (HL) and non-Hodgkin (NHL) lymphoma, plus chronic lymphocytic leukaemia (CLL – which has only been classified as a type of lymphoma in the last decade).

NHL is the most common and it is made up of two main groups: high-grade lymphomas which tend to be more aggressive and have greater potential of being treated and cured, and low-grade lymphomas, which usually remain indolent and are often not cured but managed as longterm conditions.



I found it difficult to come to terms with the treatment plan they had for me. They weren't going to do anything about the cancer straightaway, but they would adopt a 'watch and wait' strategy. It felt more like 'wait and worry'.

Andy, diagnosed with follicular lymphoma.

Most people think I am cured, and knowing that I will never be cured has been a really big hurdle to get over.

Pat, diagnosed with follicular lymphoma.



Every 28 minutes, someone is diagnosed with lymphoma. That's more than 18,000 people every year.

 **125k**

There are 125,000 people currently living with lymphoma in the United Kingdom.



It is the fifth most common cancer in the United Kingdom.



It is the most common cancer in teenagers and young adults (15-24 year olds)

>60

There are more than 60 different subtypes of lymphoma, making specialised support vital.



17 people die every day from lymphoma in the United Kingdom, that's around 6,000 people every year

Despite an improved understanding of lymphoma, there remains a disparity between the experience of lymphoma patients and that of other cancer types. This is where we need your help to drive change.

While the diagnosis, treatment and management of lymphoma in the UK have all improved over time, we continue to have poorer outcomes than countries of similar wealth and universal health coverage, such as Sweden, Australia and Canada. This is a clear indication that more can be done.



I first noticed symptoms six months previous to the diagnosis and had to visit my GP several times. My symptoms were typical of lymphoma and I felt it should have been identified much earlier than it was.

Kat, diagnosed with B-cell NHL.

We hear first-hand from patients and healthcare professionals that the key areas that need to be addressed are:

Improving patient experience

More than one third of lymphoma patients said their health got worse while waiting for their first appointment with a hospital doctor, compared to one fifth for all cancers in the Cancer Patient Experience Survey (CPES 2013)

Survival rates

Only half of people are surviving the most common subtype of NHL, diffuse large B-cell lymphoma. Specific subtypes still have low survival compared to cancer overall.

Psychological support

Our service users tell us that they are not receiving adequate levels of psychological support. This is essential, particularly for those lymphoma patients told to 'watch and wait' or those with long term incurable 'chronic' lymphoma.

Furthermore, the need for such support will grow as the number of people living with lymphoma increases.

What needs to be done?

We need your help to drive necessary change in policy and practice that will radically transform the experiences of those affected by lymphoma.

Improve diagnosis

We need a commitment to research and develop a better risk assessment and diagnostic process for lymphoma in primary care populations. We need to improve our ability to accurately diagnose specific subtypes. This is incredibly important given that different disease subtypes will react best to different available treatments.

Psychological support

We need a commitment to ensure lymphoma patients have guaranteed access to appropriate and adequate psychological support services. Lymphoma is a unique cancer experience. It requires specific support to help patients cope with the effects of the disease and move on to leading normal lives.

Better data collection

We need a commitment to ensuring the accurate collection of cancer registry data for lymphomas, so that full, proper and informative analysis of diagnosis, staging and treatment can take place. Without reliable data, improvements in diagnosis, treatment and outcomes will be slower and much reduced.

Collaboration

We need a commitment to ensure the NHS works more closely, collaboratively and supportively with the voluntary sector. The NHS is under considerable pressure. We can help ease the burden. Those charged with commissioning services should realise the value in voluntary sector service provision, such as specialist patient education, that go beyond what can be achieved by the NHS alone.

How can you help?

We can help you understand the situation for lymphoma patients in your area, and their experiences of local cancer care. With this information, you can help drive improvements for your constituents.



I remember the panic I felt when I knew my treatment had come to an end. During chemo and radiotherapy, I just carried on, but afterwards I felt so abnormal. I was almost relieved when I was told that my type of low-grade lymphoma meant I would be kept under hospital review, as I knew then that I would have continued support and advice.

Sharon, diagnosed with NHL.

Join Us today and help people affected by lymphoma in your constituency.

Contact communications@lymphomas.org.uk

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