



Lymphoma
association

Supporting
people affected
by lymphatic
cancer in 2015
A year in review



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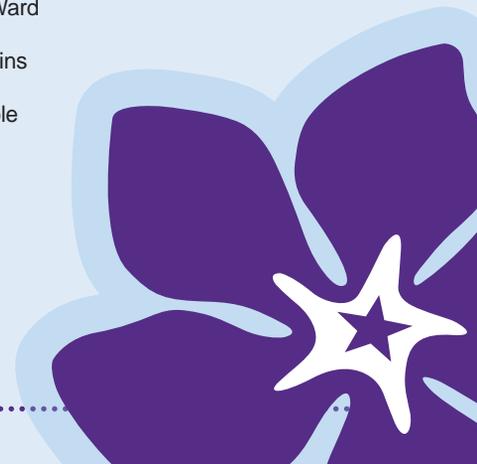
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A year in review 2015

Lymphoma is the fifth most common cancer in the UK. And the number of people living with lymphoma is increasing. When someone is first diagnosed they often have little understanding of what their illness is. They come to us for information, to learn more about the disease and their treatment options, to talk about and share their experiences, or to raise money to fund our support programmes. We give a voice to people affected by lymphoma and their experiences, and we support the healthcare professionals who look after them.

Everything that we do is rooted in patient experience. We help people through their diagnoses, their treatment, follow-up and beyond – when they are faced with the challenge of returning to a new ‘normal’ as life will never be the same again. By doing this, we reduce the demands on the NHS, saving money and time, and significantly improve patient experiences.

We continue to contribute to key forums and networks including the Lymphoma Coalition, Cancer Campaigning Group, Cancer52, Blood Cancers Alliance and the European Cancer Organisation.

In 2015, we received no government grants or funding – our work and all we have been



able to achieve over the last year is thanks to our supporters.

Thank you.

A handwritten signature in black ink that reads "Jonathan Pearce". The signature is fluid and cursive, with a large loop at the end.

Jonathan Pearce
Chief Executive
Lymphoma Association

“I attend a Lymphoma Association support group, which I find particularly helpful. With a rare disease, and especially rare in someone young, it has been helpful meeting other people in the same position and talking with others on ‘watch and wait’ like me.” Emma (pictured with her son Joel) was diagnosed with splenic marginal zone lymphoma



The first time we speak to someone it can be very emotional – people can be scared. They have often just received a life changing diagnosis.



Thanks to you in 2015...

Our Information and Support team provided a listening ear to

6,900

people affected by lymphoma – offering support, information and reassurance through the helpline, online chat and email.

Our strong community networks meant that

2,500

lymphoma patients and loved ones were able to meet others affected by lymphoma through our local support groups and benefit from the empathy and understanding that a shared experience can bring.

Compared to the previous year, we were able to double the number of people –

130

– affected by lymphoma that we matched with our buddies, volunteers who are also directly affected by lymphoma and who we train to provide peer support by telephone and email.

In 2016, we plan to expand our regional presence, launch more support groups and increase attendance to enable people to share their personal experiences. We also plan to make at least 200 buddy matches for people affected by lymphoma who need someone to talk to. We will embed our 'Live Your Life – living with and beyond lymphoma' programme, which helps patients and families to come to terms with their illness and its impact on their lives and manage their health and wellbeing in the longer-term.

Very often someone's first contact with us is online – via our website, emails or live chat service.

Thanks to you in 2015...

Our website helped us reach people affected by lymphoma who prefer the anonymity of online information and support or may not feel ready to talk to someone, as well as healthcare professionals who download our booklets and information sheets.

Almost

670,000

people were able to use our website to have their questions answered, receive reassurance and find out more information about their lymphoma diagnosis.

More than

9,000

people shared their experiences and found support by talking to someone else affected by lymphoma on our online forums.



In 2016, we will launch a further five online support groups via social media to offer localised or disease specific insight and support for people affected by lymphoma. We also want to offer a more personalised web experience for users, so they can access the information they need more easily. We will increase our campaigning and awareness raising work which includes using social media to raise the profile of lymphoma, the symptoms, the 60 subtypes and the patient experience.





Noreen met her buddy Eileen for the first time at our Beacons of Hope Awards.

“Eileen has become a very good friend through the buddy scheme, even though we live a great distance apart and had never met until the evening of the Beacon of Hope Awards. We still correspond regularly not only as buddies but also as friends, celebrating the highlights in our lives!” **Noreen**



Tanya kicked off her fundraising in aid of the Lymphoma Association with the London to Brighton walk when her husband Michael was diagnosed with Hodgkin lymphoma.

“I felt it was not only my duty but my privilege to back her to the hilt, offer her all the support possible and to let people know that there are absolute stars like Tanya and the Lymphoma Association that are here to help, encourage and support those in need when they need it!” Michael

People affected by lymphoma come to us for guidance throughout their journey – they trust us.

Thanks to you in 2015...

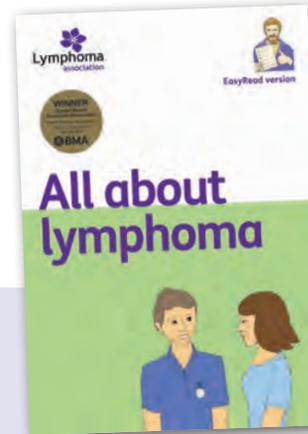
We were able to listen to the needs of callers to our helpline, people using our forums and support groups and health professionals and be responsive to these emerging needs by publishing new information in different ways.

Lymphoma is the most common cancer among teenagers and young adults and the third most common cancer in children. We expanded our suite of information specifically for children and young people and their carers, including our 'Tom has Lymphoma' story book, which was produced in partnership with CLIC Sargent.

More than

55,000

information sheets and booklets were either mailed out to or downloaded from our website by people affected by lymphoma or healthcare professionals last year.



We presented our information in new accessible formats. Our Easy Read booklet – aimed at people with learning disabilities or lower literacy levels – won a 2015 British Medical Association Award in the learning disabled category.

In 2016, we will develop a clinical trials database and information service – Lymphoma TrialsLink – which is the first patient friendly and lymphoma specific source of comprehensive trials information in the UK. We will increase the accessibility of our materials, providing them in alternative formats. We will also recruit a clinical psychologist to expand the one to one support we offer.

It matters to patients that their medical team has access to the most up to date information and lymphoma-specific training.

Thanks to you in 2015...

We were able to offer a comprehensive lymphoma training and education programme attended by

238

healthcare professionals, all of whom said they would recommend the course they attended to their colleagues. We recognise how vital it is that nurses and doctors have the opportunity to enhance their knowledge and update their skills to provide the best possible outcomes for their lymphoma patients.

We ran six educational events, including introductory study days for nurses, masterclasses for lymphoma clinical nurse specialists and a two-day lymphoma management course for specialist trainees – the lymphoma consultants of the future.

More than a quarter of non-Hodgkin lymphoma diagnoses are made in A&E. To increase the number of referrals made in primary care, we launched our first online training module aimed at GPs –

300

GPs have so far completed the course.



In 2016 we will double the size of our education and training programme, develop an online training programme to include webinars, and gain further professional learning accreditation for our training programmes.



“Lymphoma is a highly complex disease with over 60 subtypes. It’s a hugely exciting time to be involved in lymphoma management and the Lymphoma Association’s training and education programme promotes consistent, high quality care for lymphoma patients.” Dr Graham Collins, Consultant Haematologist & Lymphoma Lead, Churchill Hospital, Oxford



Our 2015 Beacons of Hope Award winners

People affected by lymphoma want to have a voice and rely on us to help change things for the better.

Thanks to you in 2015...

Our Reader Panel helps review our publications, webpages and information sheets to ensure that they are user friendly and address the needs of lymphoma patients. We increased our Reader Panel volunteers to

76

We represented lymphoma patients as active members of a number of cancer and health umbrella groups which lobby on behalf of cancer patients and their carers.

We launched our Patient Advisory Group scheme – we recruited more than

50

people affected by lymphoma to advise, guide and inspire us in how we grow and deliver support and information, improve our planning and our work for people affected by lymphoma.

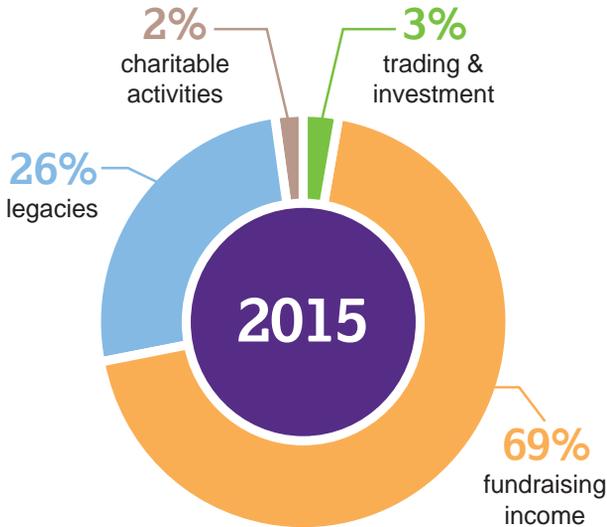


In 2016 we will hold more regional conferences, campaign on subtypes and work in partnership with Quality Health on a survey into lymphoma patients' experiences. We will also launch our first policy report that outlines key recommendations for policy change that we believe the government, the NHS and policy makers need to make to improve outcomes for people affected by lymphoma.



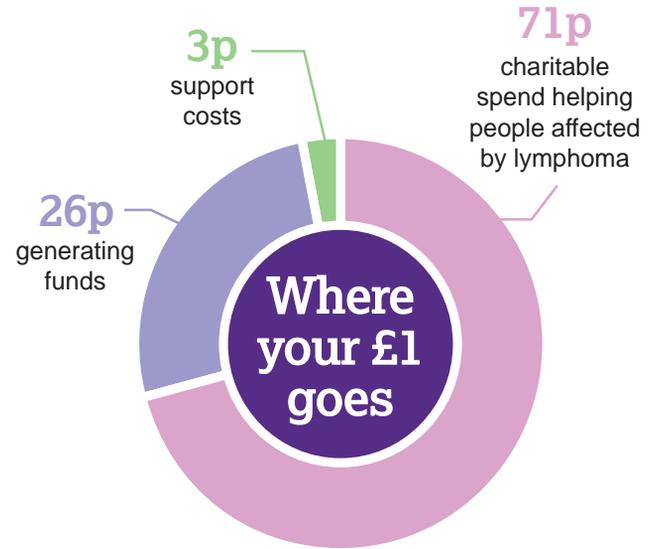
How we raised our money in 2015

Our income last year was £1,500,165.



How we spent it

In 2015 we spent £1,457,668. Out of every pound, 71p was spent directly on helping people affected by lymphoma.



“I will be eternally grateful to the Lymphoma Association. They gave me phenomenal support.”

Everything we do is made possible by the support we receive from people like you. Thank you.

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Supporting people affected by lymphatic cancer



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