

How we supported people
affected by
**lymphatic
cancer**
during 2014



Lymphoma
association

Being diagnosed with cancer can be one of the most terrifying and isolating experiences that a person can face. That diagnosis and subsequent treatment can have a devastating effect on an individual and will send out ripples through their network of friends and family.

Lymphoma is a form of blood cancer. Every year, over 14,000 new cases are identified in the UK alone, making it the fifth most common cancer diagnosed overall. Whilst it is most prevalent in people over the age of 55, it is the most common cancer in teenagers and young adults.



There are more than 60 different types of lymphoma, making specialised information and support so important.

There is nothing like receiving a cancer diagnosis. There is nothing like hearing that someone you love has cancer.



'I can still remember so clearly my dad's face when we came out of that consultation – thinking about that makes me feel tearful even now.'

Carol, diagnosed with lymphoma in 2004

We want everyone affected by lymphoma to receive the best possible information and support, treatment and care. We aim to do this by:

- › providing information and support to anyone affected by lymphoma
- › raising awareness of lymphoma and its symptoms
- › representing patients' views to policy and decision-makers
- › providing information, education and training to health professionals
- › collaborating effectively with health bodies and other charities and organisations.

Everything the Lymphoma Association does is specifically for people affected by lymphoma. We are the only UK charity solely dedicated to lymphoma and that's what makes us so special. But we rely totally on donations and without additional funds we are limited in what we can do.

Thank you to all those who helped raise money in 2014. Every penny counts in giving information and support to another person facing that terrifying and isolating experience of cancer.



Here's what we achieved in 2014...

Living with lymphoma can be an isolating experience. People need support in different ways. Our dedicated helpline allows people to call us, email or chat online. Other people want the support of others going through a similar experience and a local support group allows them to meet regularly with others in their area. The buddy scheme puts people in contact with others going through a closely matched experience.



Empowering people

Here's what people who used our helpline told us last year:

95%

said the helpline were able to answer their questions or concerns

100%

said the medical information provided helped them better understand their situation

95%

felt the conversation helped them feel more in control of their situation

90%

said that after their conversation with the helpline they had more confidence to speak to their medical team.

100%

would recommend the Lymphoma Association helpline to others.



'No amount of preparation for the news actually helped. At the hospital, I knew there were many questions I needed to ask, and yet, in that instant, I could not think of a single one. That is where the Lymphoma Association helpline and website came in.'

Julian, diagnosed with low-grade nodal marginal zone lymphoma in 2014



'I used the Lymphoma Association throughout my treatment. The helpline were so knowledgeable and reassuring and the website was logical and easy to use. What was so helpful was to find a source of information and support that I could trust and that was specific to my needs.'

Sharon, diagnosed with non-Hodgkin lymphoma in 2003, with her husband Mike

Providing the best possible information and support

Finding the right support and information can make all the difference in helping people to cope. That's why we make it available to everyone who needs it – in as many ways as possible.

We had
324,512
unique visitors to our website in 2014 - 56% more than the year before. Our continuous website improvements ensure we are user-friendly.

Lymphoma Association information is certified with the Information Standard, a quality scheme supported by the Department of Health.

Two of our books were
Highly commended
at the 2014 British Medical Association Patient Information Awards.



Information is available online, in print, as audio, e-book or through NHS Choices – all at no charge.

f22,282 Facebook fans

We reached 70% more people via Facebook and Twitter in 2014.

3,174 Twitter followers

46,314 copies of our magazine *Lymphoma matters* were sent out in 2014, providing people with medical information, tips and ideas.

‘The Support Group has given me the power to open up and talk about my lymphoma and it’s great to be able to speak with other people with the same illness.’

Being able to talk to others affected by lymphoma

The 42 Lymphoma Association support groups welcome anyone affected by lymphoma – from newly diagnosed to those who received treatment 30 years ago or more. During 2014, around 2,500 people were able to meet others, hear talks and share experiences at meetings in their area.

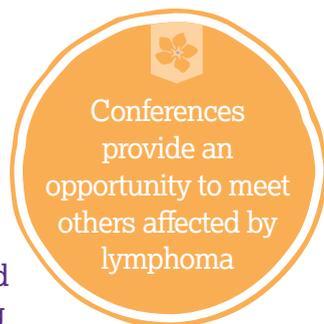


Conferences

Nearly 200 people joined us in Leeds in 2014 to learn from the wisdom, experience and insight of the haemato-oncology team at St James’s hospital. We also ran a joint conference with Leukaemia CARE in London where nearly 100 people were able to hear inspiring talks, share experiences and meet others.

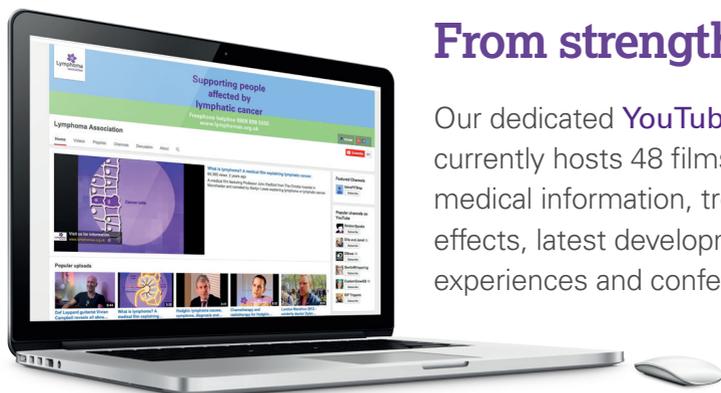
‘I left the conference a changed man. I know this sounds a bit dramatic but I feel much better equipped to manage the challenges that my illness and the treatment have thrown at me. Even at work this week I have experienced a quiet confidence and tranquil calm in delivering my business which I was unused to before.’

Richard, who attended our conference in Leeds in 2014



From strength to strength

Our dedicated YouTube channel currently hosts 48 films covering medical information, treatments, side effects, latest developments, personal experiences and conference talks.



48
films



Our films were viewed over 130,000 times in 2014, an increase of 114% over the year before.

‘Sometimes you feel like the only person in the world going through this. Watching the films makes you realise that others are going through the same thing and it is reassuring because they have come out the other side.’

Adam, diagnosed with Hodgkin lymphoma in 2013

‘We knew nothing about lymphoma, but understanding the disease has made it less frightening. The Lymphoma Association is great because it provides the information you need as well as offering a support network at the end of the phone.’

Jan, diagnosed with lymphoma in 2009, with her daughter Liz



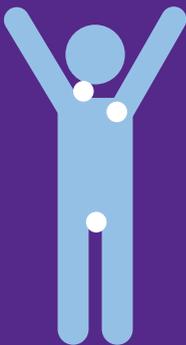


Educational resources for health professionals

Our training courses for health professionals are aimed at all levels. In 2014 we held three study days for nurses in Stirling, Cardiff and London. As one nurse in Cardiff commented: 'I feel my knowledge of lymphoma has greatly increased; the day was very relevant to my work.'

Raising awareness and influencing policy

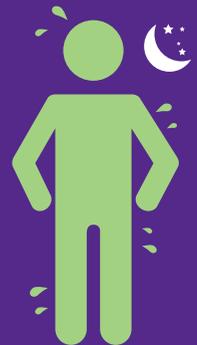
We reached almost 227,000 people with a signs and symptoms of lymphoma infographic (see below) that we launched during Lymphatic Cancer Awareness Week, giving people the best chance of getting an early diagnosis and treatment.



A lump in your neck, armpit or groin?



Losing weight but don't know why?



Drenched in sweat during the night?

PITS student campaign



Because lymphoma is the most common cancer in people under the age of 35, we attended 10 university freshers' fairs to tell students about the signs and symptoms. As a result, 97% said they would visit a doctor if they experienced any of the symptoms we told them about.

Ensuring the patient's voice is heard

During 2014 we engaged in lobbying, campaigning and policy-related activities to ensure the voice of people affected by lymphoma was heard. We contributed to a number of NICE cancer drug treatment technology appraisals as well as consultations around value-based assessment of drug treatments. We were involved in discussions around the Cancer Drugs Fund and continued to participate in campaigning groups such as Cancer 52 and the Cancer Campaigning Group. Towards the end of 2014 our chief executive, Jonathan Pearce, was elected to the Executive Board of the Lymphoma Coalition, an international collaboration of patient groups.

Itching all the
time but don't
know why?



**If you're experiencing
any of these symptoms,
have them checked out
by your doctor. Lymphoma
can be treated,
so act now.**



Lymphoma
association

‘The Lymphoma Association saved my life.’

‘On 3 August 2009 I was diagnosed with stage I primary mediastinal large B-cell lymphoma – a type of non-Hodgkin lymphoma. I was 42 years old. I felt ill very soon after the first round of chemotherapy. At the start of the second cycle of chemotherapy I felt very weak and as I looked around at other people who seemed to be coping much better than me, I thought this meant that my treatment wasn’t working.’

The effect of the chemotherapy was cumulative and by the third cycle I felt I just couldn’t do it anymore. I was lying on the floor, unable to do anything for myself. I couldn’t string a sentence together. I couldn’t even wash myself.

Tracey, diagnosed
with lymphoma
in 2009



Calling the Lymphoma Association helpline

The specialist nurse suggested I contact the Lymphoma Association. I called them and found their helpline supportive and informative. It was so reassuring to be able to talk with someone who explained about the many different types of lymphoma and the different treatment strategies.

My Lymphoma Association buddy

The Lymphoma Association suggested that I might benefit from talking with a 'buddy' – someone else who has been through a similar experience. In truth, I was at the end of the line. I really felt I couldn't face any more treatment at all.

Lymphoma – especially a rarer type – feels like a very isolating disease and I had not come across anyone with the same type as me. I needed to care for my son and, although my dad was happy to help with practical issues, he really didn't know what to say to me.

Talking to the Lymphoma Association buddy saved my life. She had been treated for the same type of lymphoma as I had. She told me that it would not always be like this. She said that at some point I would look back and say 'I don't know how I got through this, but I did'. And she knew, because she'd got through it. She never told me to pull myself together, she never told me it would all be OK - and I was grateful for that. But she was there and she had been through this herself.

That conversation was a life-saver. She wasn't emotionally connected to me, so I could talk to her openly and honestly, without feeling I needed to protect her or tell her what she would want to hear. I was tired of people telling me it would all be alright.

I put the phone down and decided I would try once again. I don't think I would be here today if I had not had that conversation.

Finding a support group

I started attending a support group near me. When I first went along I had no hair, and it was just lovely because I didn't have to explain to anyone why I was bald. I was made so welcome and found the group enormously supportive.

What now?

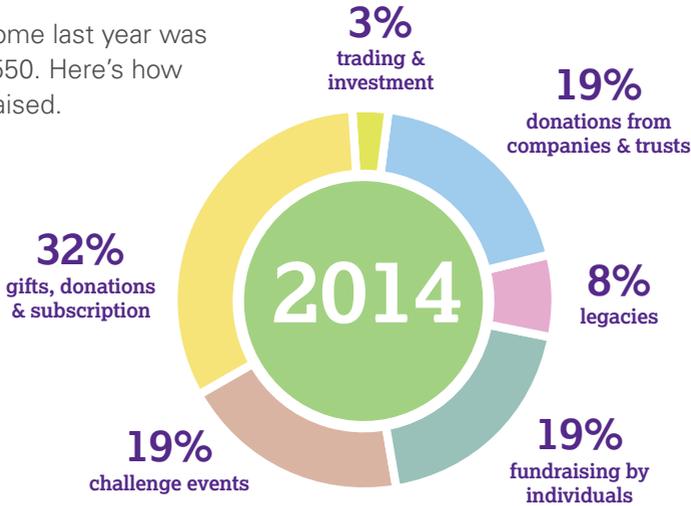
We have recently celebrated my son's 21st birthday.

I wanted to make it special for him and it certainly was a night to remember! And I have been back in contact with the buddy who saved my life. She is doing well too and it was great to have a chance to thank her and tell her just what that conversation meant to me.'



How we raised our money in 2014

Our income last year was £1,184,550. Here's how it was raised.



How we spent it

In 2014, we spent £1,277,276. Out of every pound, 77p was spent directly on helping people with lymphatic cancer.



Everything we do is made possible by the support we receive from people like you. We really couldn't be more grateful.

'Thank you so much, Lymphoma Association – you have helped me turn my life around.'



Our corporate and trust supporters

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Professor David Linch

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John Fulton, Treasurer (resigned Jul 2014)
Steve Dunn – Treasurer (appointed Sep 2014 as both trustee and treasurer)
David Barnett, Chair –
investment committee
Dr Graham Collins
June Cook (appointed Sep 2014)
Mark Edwards (resigned Feb 2014)
Mark Harrison
Felicity Hilder OBE
Nicola King (appointed Sep 2014)
Richard Morris (retired Sep 2014)
Burton Paul (appointed Sep 2014)
Dr Benjamin Riley
Pascale Wood-Atkins (resigned Oct 2014)

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Jonathan Pearce

Secretary

Val Evans (resigned 11 Jul 2014)
Jonathan Pearce (appointed 11 Jul 2014)

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Dr Adrian Bloor
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Professor David Cunningham
Professor Stephen Devereux
Professor Martin Dyer
Dr Paul Fields
Dr Eve Gallop-Evans
Dr Georgina Hall
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Professor Simon Rule
Dr Andrew Wotherspoon

Looking to the future

'We have achieved a great deal during 2014, yet much remains to be done. Through our work in the future we want to help people find the knowledge, the support and the network they need to continue with their lives and their fight against cancer.'

During 2014, we completed a major strategic review that formed the basis of our new three-year business plan which will take us through to 2018. We want to make a major impact in improving the lives of people affected by lymphoma by:

Building a thriving online community

Building on the success of our online forums and our 'Digital First' approach, we aim to develop our website into a thriving online community.

Providing local support

From our existing network of support groups, we plan to provide higher levels of support, education and training at a regional level. This will also involve the development of a 'Live your life – living with and beyond lymphoma' education and training programme.

Delivering education and training

By extending and expanding our existing programme of events, we aim to provide more learning opportunities for people affected by lymphoma, and also for healthcare professionals.

Offering psychological support and counselling

Lymphoma is a complex disease with counterintuitive traits and characteristics. There is a psychological impact, as well as a physical one; there are gaps in NHS services around emotional and psychological support. It's no wonder then that our supporters are asking us to fill these gaps and meet that need.

There is even more we can do to support the 90,000 people living with lymphoma, but without additional funds this may be limited. Our plans are ambitious and we want you to share that ambition.'



Chief Executive

Lymphoma Association
3 Cromwell Court
New Street
Aylesbury
Bucks
HP20 2PB

Tel: 01296 619400
Freephone helpline: 0808 808 5555
information@lymphomas.org.uk

www.lymphomas.org.uk

Registered charity no 1068395

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**Supporting
people affected by
lymphatic cancer**