

# lymphoma matters

ISSUE 113 | SPRING 2019

**Volunteering opportunities**

**Update on diffuse large B-cell lymphoma**

**Chemo brain**

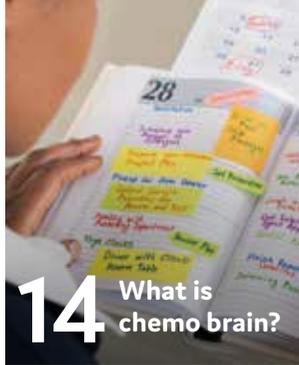
**Lymphoma**  
**action** 



**06** Diffuse large B-cell lymphoma



**12** Mary's experience of chemo brain



**14** What is chemo brain?



**20** Stuart's experience of Hodgkin lymphoma



**22** What is a normal response to cancer?



**26** Update on clinical trials

## Contents

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among people aged 15-24. We've been providing in-depth, expert information and wide-ranging support for over 30 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment and aftercare of lymphoma. We're here for you.

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Editor: Anne Hook

Cover: Fundraisers who climbed Ben Nevis

**04** Latest news

Current news and developments

**10** Challenge events

Get involved

**18** Community fundraising

Ideas and dates for your diary

**30** Volunteers

Our survey into volunteering

**32** Support groups and helpline

How we can support you

**34** Ask the expert

Questions about clinical trials

To make a comment, to sign up, or to unsubscribe to the magazine, email [publications@lymphoma-action.org.uk](mailto:publications@lymphoma-action.org.uk) or telephone 01296 619400.

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Ropinder Gill  
Chief Executive

Help shape our magazine by filling in our survey enclosed or go to [www.surveymonkey.co.uk/r/LM19](http://www.surveymonkey.co.uk/r/LM19)



We hope you like this edition of *Lymphoma Matters*. You can sign up to regularly receive our magazine at [www.lymphoma-action.org.uk/SignUp](http://www.lymphoma-action.org.uk/SignUp)

# Long-term plans

**With the publication of the NHS ten-year plan, the Government has set out a number of priorities for the future of cancer care.**

With our patient focus, we were able to represent the needs of people affected by lymphoma during the consultation stage. Whilst we were pleased to see the more personalised and co-ordinated approach to cancer care in general, we want the Government to commit to providing the resources and workforce we believe are needed to make the long-term plans a reality for patients.

Resources are a pressure for everyone. As a charity we certainly understand this, which is why it is important to us that every penny you donate goes towards providing the services that make a real difference to people affected by lymphoma. These services include our award-winning Live your Life programme, which helps people live with and beyond their lymphoma, our care and support services and our relevant and up-to-date information, including videos and animations.

We can only continue to meet your needs if you share what those needs are. That is why I would urge you to complete and return the enclosed survey to help us make our magazine better for you and others affected by lymphoma. You can also fill the survey in online at [www.surveymonkey.co.uk/r/LM19](http://www.surveymonkey.co.uk/r/LM19)

Lastly, I would like to thank everyone who supported us through our special Treasurers appeal and other Christmas initiatives. Your generosity has given us the tremendous boost we needed going into 2019.

Please enjoy this first 2019 edition of *Lymphoma Matters* magazine and I look forward to meeting you this year at events, such as our National Conference on Saturday 11 May or our Bridges of London Walk on Sunday 12 May.

Ropinder Gill  
Chief Executive

# NHS launches new ten-year plan

The NHS launched its new ten-year plan on 7 January 2019 following consultation with the public, staff, service users and organisations including Lymphoma Action.

Whilst lymphoma was not specifically mentioned, we are delighted that many of the recommendations we made appear in the plan.

There is a shift that suggests a more personalised, coordinated approach to cancer care in general, including:

- Faster, accurate diagnoses through the roll-out of Rapid Diagnostic Centres for people with symptoms associated with cancer.
- From 2020, most patients to receive a definitive diagnosis, ruling out cancer within 28 days of referral.
- Within the next three years, every patient will receive an individual care plan covering a needs assessment and access to information and ongoing support.
- DNA testing for children with cancer to understand specific conditions better and prescribe the most

effective treatment. The plan aims to extend the use of molecular diagnostics in adults and, over the next ten years, routinely offer

genomic testing to all people with cancer for whom it would be of clinical benefit.

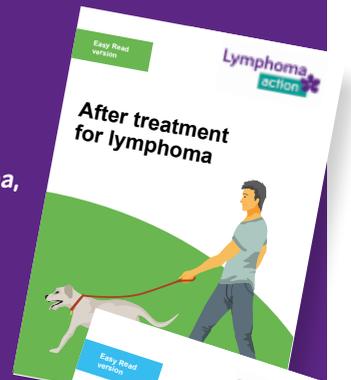
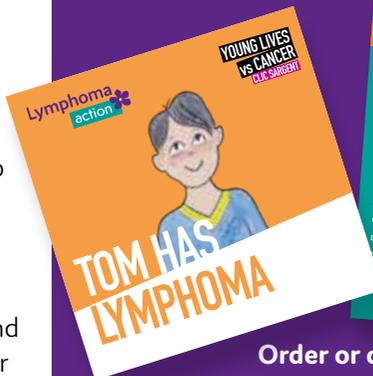
- Integrated Care Systems to bring together local organisations involved in healthcare – GPs, hospital clinicians and charities.
- Improved access to clinical trials.

Lymphoma Action chief executive Ropinder Gill commented: 'We are very glad to see a more personalised and coordinated approach to cancer care in the NHS ten-year plan.'

## New booklets now available

We have revised *Clinical trials for lymphoma* and *Tom has lymphoma*, a storybook for children. We have also just published four Easy Read booklets:

- *Finding out you have lymphoma*
- *Watch and wait for lymphoma*
- *Treatment for lymphoma*
- *After treatment for lymphoma*



Order or download our booklets at [lymphoma-action.org.uk/Shop](http://lymphoma-action.org.uk/Shop)



## Lymphoma Action shortlisted for Charity Film Award

We're delighted our animation explaining lymphoma to children has been shortlisted in the Charity Film Awards.



Ropinder Gill, our chief executive, explains: 'We're often asked to help parents who need to talk to children about a lymphoma diagnosis in the family. Their feedback suggested that a simple, visual approach would help to put this complicated condition across to children in a way that was reassuring and easy to understand. Our animation, voiced by a child, covers what lymphoma is, the kind of treatment someone might have for lymphoma and how a lymphoma diagnosis might affect day-to-day life.' Watch at [www.youtube.com/LymphomaAction](http://www.youtube.com/LymphomaAction)

## Live your Life programme wins award

Our Live your Life programme has been awarded an AbbVie Big Ideas for Better Health Award 2018.

The Awards were launched by the biopharmaceutical company AbbVie in 2015 to recognise, celebrate and share exceptional examples of healthcare improvements and innovation that demonstrate clear benefit to the lives of patients. Our Live your Life programme was recognised in the 'Supporting Self-Management and Self-Care' category for addressing a real area of unmet need – post-treatment support for people living with lymphoma.

Stephen Scowcroft, director of business development at Lymphoma Action said: 'We are delighted to have won this award. Our Live your Life programme has allowed us to offer additional support and activities to help people take control and find their 'new normal'. 100% of attendees say they learned what they can do to live better during and after lymphoma and 97% said they feel more confident in recognising signs and symptoms that should be reported to healthcare professionals.'

Find out more about Live your Life at [www.lymphoma-action.org.uk/LYL](http://www.lymphoma-action.org.uk/LYL)



*Stephen Scowcroft, director of business development at Lymphoma Action (left) with MP Henry Smith, chair of the All-Party Parliamentary Group on Blood Cancer, at the awards ceremony at the House of Commons in London on 20 November 2018.*



# Diffuse large B-cell lymphoma

from there to here;  
from here to the future

Survival for people with **diffuse large B-cell lymphoma (DLBCL)** has improved dramatically since the 1960s, making management of DLBCL one of the great success stories in lymphoma care. At the lymphoma clinical studies group (CSG) annual clinical trials meeting, Professor David Linch outlined how this progress has been achieved and where research is heading.

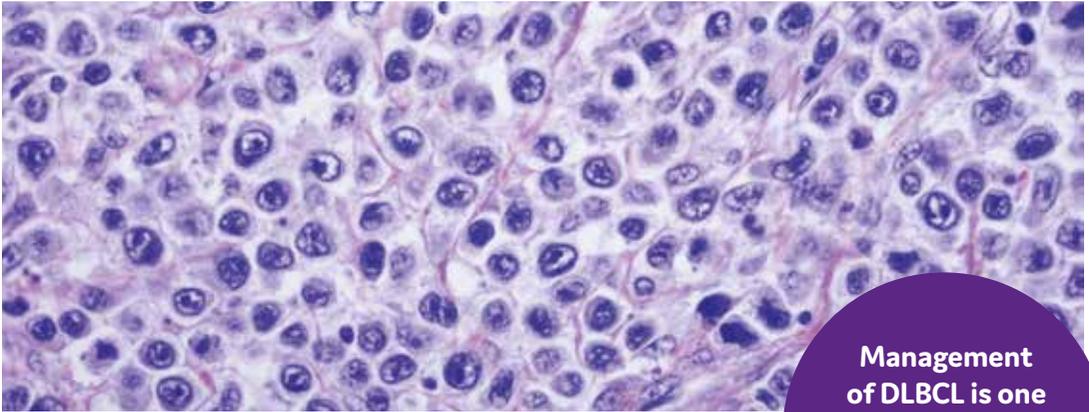
The distinction between Hodgkin lymphoma, non-

Hodgkin lymphoma (NHL) and leukaemia was not made until 1925. DLBCL, the most common type of high-grade non-Hodgkin lymphoma, was not firmly accepted as a specific diagnosis until 1994.

The incidence of NHL has been increasing since the 1970s, mostly occurring in older people, with an average age at diagnosis of over 65. The increasing incidence of NHL may have much to do with an ageing population as well as improvements in diagnosis.

## Treatment: from there to here

Early-stage (localised to one place) DLBCL was originally treated with radiotherapy (treatment with powerful X-rays) alone, but some people did not completely respond to radiotherapy. The standard treatment plan was changed to include chemotherapy (treatment with drugs) as well as radiotherapy, and later the antibody treatment rituximab was added. This combination works well and stage 1A DLBCL can



Management of DLBCL is one of the great success stories in lymphoma care.

be treated very effectively. However, it is noteworthy, that studies of people treated only with radiotherapy showed that most people whose lymphoma got worse had lymphoma growing outside of the area that was treated with radiotherapy. It is possible that these people were not staged correctly and actually had more widespread lymphoma than was thought.

The outlook for people with more widespread lymphoma was much worse historically. However, in the 1970s, treatment with a combination of chemotherapy drugs known as 'CHOP' was introduced, and long-term survival improved dramatically. CHOP remains the backbone of treatment for DLBCL. Around two-thirds of people are now successfully treated, but this varies greatly according to factors such as age and stage of the lymphoma. Outcomes have improved over the decades

since CHOP was introduced due to several factors.

### 1. Improved supportive care and expertise:

Improvements in antibiotics to prevent infection, the introduction of growth factors (G-CSF) to boost blood counts, and increased availability of intensive care have all helped to support people through their lymphoma treatment. These improvements also allow more people to have the full course of treatment, as doses do not have to be reduced or delayed due to side effects. Greater medical specialisation and multi-disciplinary teams (where health professionals with different areas of expertise work together) also mean that people affected by DLBCL are now getting expert care.

### 2. Addition of rituximab to CHOP:

The combination of rituximab with CHOP chemotherapy was first approved to treat DLBCL in 2006. The R-CHOP regimen has now been in widespread use for more than a decade and has significantly improved outcomes for people with DLBCL.

### 3. High-dose salvage and stem cell transplants:

Around half the people whose lymphoma relapses (comes back) go back into remission (no evidence of lymphoma) when given a different chemotherapy (salvage) followed by high-dose chemotherapy and

The R-CHOP regimen has been in widespread use for more than a decade and has significantly improved outcomes for people with DLBCL.



a stem cell transplant. There are lots of effective salvage chemotherapy regimens for people whose lymphoma is still sensitive to chemotherapy. Notably, as first-line treatment has improved, the people who need salvage chemotherapy tend to be those with lymphoma that is more difficult-to-treat. Sometimes, DLBCL does not respond to chemotherapy and more treatment options are needed for these people.

#### 4. Improvements in imaging:

CT scans were first introduced in the 1970s and they have made it much easier to diagnose lymphoma found deep inside the body. Previously, explorative surgery may have been the only way to diagnose a lymphoma, and many people would have been monitored for much longer before diagnosis if this was needed. PET scanning has also helped improve staging, which is particularly important in identifying people who are stage 1 and need different treatment to those with more widespread lymphoma.

#### Treatment: from here to the future

There have been many attempts to improve on

the CHOP backbone over the years. Adding different drugs or using different dosing schedules does not seem to have much impact. For example, there is no difference in outcomes when R-CHOP is given every 2 weeks compared with every 3 weeks. Dramatic improvements in chemotherapy and supportive care are not expected. Although newer antibodies that have the same target as

rituximab have been developed, they don't offer much improvement in outcomes for people with DLBCL.

#### Cell-free DNA

(sometimes called 'liquid biopsy') has growing interest as a possible tool to help predict if someone is likely to relapse. Cell-free DNA is DNA from the lymphoma that can be found circulating in the blood. Research suggests that people who have a sharp decrease in the levels of cell-free DNA in a blood sample taken after their first two cycles of chemotherapy have a better outcome than those whose cell-free DNA does not decrease as dramatically. People with high levels of cell-free DNA after treatment have a

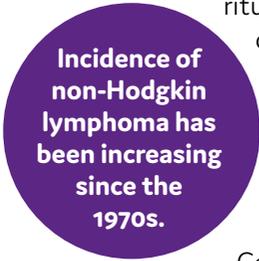
higher chance of relapse. This knowledge could help specialists decide if people need more treatment or monitoring.

For stage 1 DLBCL, improvements in staging mean it may be possible to re-consider whether radiotherapy or even surgery alone are enough to cure most people. Those who relapse would still be able to have chemotherapy and rituximab.

For more widespread DLBCL, people who do not respond to chemotherapy have the greatest need for new treatments. It is likely that it will be targeted treatments that drive forward progress for these people.

Targeted treatments affect processes in cells. They work in different ways to stop cancer cells growing or dividing, to cause cancer cells to die or to use your own immune system to help your body get rid of cancer cells. As they work in a different way to chemotherapy, which usually targets dividing cells, they can be effective for people who need a different type of treatment.

Many targeted treatments already used for other types of lymphoma are being tested for DLBCL,





including ibrutinib, idelalisib and venetoclax. However more research is needed as it seems that only certain groups of people with DLBCL might benefit, or that these drugs might be best used in combination with other treatments such as rituximab or chemotherapy.

Antibody-toxin conjugates, for example polatuzumab vedotin, are being tested as possible treatments for DLBCL. Polatuzumab vedotin comprises an antibody together with a chemotherapy drug, so the antibody can deliver the drug directly to the lymphoma cells.

Treatments that harness the power of your T cells are of great interest in treating DLBCL. T cells are a type of lymphocyte in your body that helps fight infection and disease, including cancer. Many cancers find ways to evade your immune system

but some new treatments for lymphoma help your T cells to recognise the lymphoma so they can destroy it. Treatments under investigation include:

- Bispecific T-cell engagers (BiTEs), which attach to a protein on lymphoma cells and also attach to T cells. Early versions of these drugs have already shown promise and the next generation should improve how long they last in the body.
- Checkpoint inhibitors, for example nivolumab and pembrolizumab, which are already used for Hodgkin lymphoma.
- CAR T cells, where your own T cells are modified so they can recognise and kill lymphoma cells. These

treatments are beginning to be approved for lymphoma but newer versions are already in development that should last longer in the body, have several targets and switches to turn them on and off.

In newer classifications of lymphoma, there is increasing emphasis on molecular aspects of the disease, which allow DLBCL to be categorised further into groups exhibiting particular genetic changes. These differences mean the lymphoma cells have different ways of surviving and multiplying. Research continues to work out the best way to pick out key differences between types of DLBCL. Unpicking these molecular differences could be crucial in knowing which treatments might work best for people with DLBCL.

**It is likely that targeted treatments will drive forward progress for people who do not respond to chemotherapy.**

With thanks to Professor David Linch, Head of Department of Haematology, University College London

**BRIDGES OF  
LONDON  
YOUR WALK  
YOUR WAY**

**Sunday 12 May**

Our first Bridges of London Walk takes place the day after our National Conference (see page 35–36) and is the perfect way to have a weekend in London and support Lymphoma Action.

Walk at your own pace across 11 of the capital's iconic bridges, finishing at Tower Bridge. This 9km (5.6 mile) walk is the perfect way to see the capital. You'll be able to take in the sites and there's time to stop and enjoy lunch by the Thames. You will even receive a medal for taking part!

This walk is suitable for all ages, giving you an experience to remember. It will be rewarding, fun and absolutely achievable.

Sign up at [www.lymphoma-action.org.uk/Bridges](http://www.lymphoma-action.org.uk/Bridges)

**PEDAL 4 CANCER**

**Sunday 8  
September**

Get together with friends and family and be part of this special 100km (60 mile) cancer bike ride. It's open to anyone over 14. The event

# Setting the pace

**IN 2019**

is not timed, and it's not a race – it's about taking on a challenge, having fun and raising funds for Lymphoma Action.

The starting point is Lee Valley VeloPark in the Queen Elizabeth Olympic Park, Stratford. You'll then head north-east into the scenic country roads of Hertfordshire and Essex before skirting the historical city of Cambridge. Visit [www.lymphoma-action.org.uk/Cycle](http://www.lymphoma-action.org.uk/Cycle)

**THE  
HACKNEY  
HALF MARATHON**

**Sunday 19 May**

The Virgin Sport Hackney Half Marathon has marked its position as one of the top ten half marathons in the UK. Hackney knows how to party and you too can take part in this great

race. The atmosphere is like a carnival with the streets lined with supporters and live entertainment. Visit [www.lymphoma-action.org.uk/Run](http://www.lymphoma-action.org.uk/Run)

**OVERSEAS CHALLENGE  
HIGH ATLAS SUMMIT  
TREK, MOROCCO**

**23-28 September**

We've already recruited our community and partnership manager and we'd love you to join this rewarding challenge. It combines the unforgettable scenery of the High Atlas Mountains with the splendour and colour of Marrakech. The trek involves climbing northern Africa's tallest peak, Jebel Toubkal, standing at 4,167m and finishes in the vibrant city of Marrakech. This is a tough challenge and a good level of fitness is essential. Visit [www.lymphoma-action.org.uk/Overseas](http://www.lymphoma-action.org.uk/Overseas)



For further information about any of these challenges, or to find out about other events, contact [fundraising@lymphoma-action.org.uk](mailto:fundraising@lymphoma-action.org.uk) or phone Adele on 01296 619419.

**PLACES AVAILABLE NOW!**

# Sausages

'Sausage is a great deal like life. You get out of it what you put into it.' *Jimmy Dean*

## Mary explains the challenges of coping with 'chemo brain' after treatment for non-Hodgkin lymphoma

'Sausages' seems an apt heading for my story as it was the humble sausage that sparked off an incident.

I'd always imagined that people with dementia forgot huge episodes of their life, not just simple, everyday words and associations. I may of course be wrong as I don't pretend to be an expert, but a recent episode gave me a small insight into what it must be like to lose part of your memory.

The anger and frustration that such gaps in memory bring was brought forcibly home to me when I recently experienced an extremely

frightening and distressing experience.

It all started so well. The sun was shining, I'd been out of hospital for eight days since my treatment and I felt an unexpected energy and desire to achieve something from the day; 'Let's go for a walk' I suggested.

Pleased at the thought of some action my husband quickly agreed. We set off towards the little village just half a mile or so away from where we lived. It felt so

good to be outdoors without the confines of walls, so when my husband suggested walking a little further I readily agreed. We walked past the old parish church, over the hump-backed stone bridge and along the small, overgrown lane that led to the museum and car park.

Reluctant to return to the confines of my home and determined to make the most of the day I encouraged my husband to walk further. Slowly we traversed the boundaries of the village and then moved

This is one of a series of articles written by Mary who was diagnosed with lymphoma in 2012. To read more, go to [www.lymphoma-action.org.uk/Mary](http://www.lymphoma-action.org.uk/Mary)

## 'Suddenly the energy needed to carry on this ridiculous conversation left me. I felt weak and drained both physically and mentally.'

onwards towards the shopping area closer to town. We were almost there when my husband innocently asked what I wanted for tea. No answer sprang immediately to mind but I remembered that we'd spoken of this just a few hours earlier.

'You know. I told you earlier,' I said. My husband tentatively enquired, 'Sausages?'

Nothing registered so I was convinced that couldn't be correct.

'You know' I repeated, feeling annoyed at myself for not being able to remember. He tried again, 'Fishfingers?'

By now, unable to find any words to help him, I resorted to hand signals, sketching out two parallel lines with my fingers.

'Stop being stupid. You know, those long, thin things with skins on.'

Once again he tried, 'Sausages.' At this point I felt really angry. I stopped walking and began using my hands to sketch out the shape again.

Suddenly the energy needed to carry on this ridiculous conversation left me. I felt

weak and drained both physically and mentally. I leant heavily against the nearest fence and said 'I need to go home.'

Trying to make conversation, my husband asked if I'd heard from Linda, a friend and work colleague. Once again, the word meant nothing to me.

'What's Linda,' I asked. Feeling seriously concerned, my husband gave up and talked about everyday, mundane subjects until we reached our house.

**By this time, I felt completely exhausted. I lay down on the settee and slept soundly for forty minutes. When I woke up I felt really hungry.**

'Are we having sausages for tea then?' It suddenly hit me as I remembered those ridiculous conversations on the way home, my frustration and anger at not being able to remember words or their associations. My symptoms were obviously only a temporary blip but how difficult must it be for people who live with it every day?

In hindsight, I had probably overdone things. Indeed, I

Luckily for me, my chemo brain was short term, but I may blame it when I next forget my computer password!



A reassuring hug from granddaughter Poppy

found out the next day on a visit to the Day Unit that this type of experience is not uncommon in those undergoing chemotherapy. In fact, there is even a name for it, chemo brain. This describes a mental cloudiness (fog) that, as in my case, can affect memory. It can also affect concentration, organisation and processing speed.

Luckily most symptoms seem to be short term. Mine certainly was, although I may blame chemo brain next time I forget my computer passwords or my next dental appointment.

Mary

# What is... cancer-related cognitive impairment or 'chemo brain'?

Learning about  
chemo brain and how  
long it usually lasts may  
help you cope better  
with symptoms.

**Cancer-related cognitive impairment is a change in thinking processes that affects some people with cancer. The changes mainly affect memory, concentration and thinking speed. It is also known as chemo brain or 'chemo fog', although it doesn't only affect people being treated with chemotherapy. All these names refer to the same thing.**

### Who gets chemo brain?

Chemo brain affects up to three-quarters of people during or soon after treatment for cancer.

About one in five people with cancer might notice the effects of chemo brain before they start any treatment at all. The effects might be more noticeable in people who also have 'B symptoms', ie unexplained weight loss, night sweats and fever.

Although it's called chemo brain, it can affect people with cancer who haven't had chemotherapy, or people who are treated with radiotherapy. At the moment, there is little research on chemo brain in people treated with newer, targeted treatments, so we do not know how – or if – these may influence thinking.

You might be more likely to be affected by chemo brain if:

- you are older – cancer itself is more common in

older people, and there are natural changes in thinking processes throughout your life, causing changes in memory, attention and thinking speed. While this is a normal part of getting older, cancer and cancer treatment can make this change in thinking processes worse. It can be hard to work out how much of the change is due to getting older and how much is due to the lymphoma and it's treatment

- you are female
- you have a longer course of chemotherapy or high-dose chemotherapy, for example prior to a stem cell transplant
- your chemotherapy is injected into the spinal canal (intrathecal chemotherapy) or directly into an artery (intra-arterial chemotherapy; this is unusual for lymphoma)
- you have certain other medical conditions, such as anaemia, heart disease or diabetes
- you have depression or anxiety. Treating anxiety and depression in people with chemo brain might help reduce the effects of chemo brain
- you already had problems

with thinking and memory before you developed cancer or started your treatment.

Some chemotherapy medicines used to treat lymphoma could be more likely to cause chemo brain than others. These include methotrexate, carmustine, melphalan, fludarabine, cytarabine and cisplatin. Most of the research is based on studies in animals and it's difficult to know whether this applies to humans.

### What causes chemo brain?

Nobody knows exactly what causes chemo brain. It's probably a combination of the effects of the cancer and of the cancer treatments. These effects include inflammation and changes to the chemicals, hormones and blood flow in your brain. Some chemotherapy drugs can damage nerve cells in your brain. Cancer and chemotherapy also cause other issues, like anaemia or infections, that can potentially affect thought processes.

Scientists think a combination of all these things affect the way your brain works when you have

**Scientists are studying chemo brain to try to find out more.**



cancer or cancer treatment. They're studying chemo brain in more detail to try to find out more.

### What are the signs of chemo brain and how might it affect me?

Chemo brain can cause changes to your memory, concentration, attention span and complex thinking processes.

Chemo brain affects different people in varying ways.

The effects are usually mild and generally get better over time. The symptoms can vary from day-to-day, at different times of day and, if you're on treatment, at different times in your treatment cycle. They are usually worse when you're tired or busy.

**Memory** – You might notice that your memory isn't as good as it was. You might forget people's names, misplace things or struggle to find the word you want to use.

**Concentration and attention span** – some people feel 'spaced out' and find it hard to focus on what they're doing. This can make everyday things difficult, like following a conversation or television programme or reading a book.

**Complex thinking processes** – thought processes you normally find easy, such as making shopping lists, doing puzzles or adding up numbers in your head, might seem harder or slower. It can also be hard to swap between tasks if you're doing more than one thing at a time. It might take you longer than usual to take in new information or learn new things.

“  
The effects of chemo brain are usually mild and generally get better 6-24 months after finishing treatment.”

**Emotional effects** – you may be embarrassed that you can't do things the way you used to or worry that friends, family and colleagues might notice the change in you.

### How is chemo brain treated?

Don't be afraid to tell your doctor or nurse. They will understand how you're feeling and can offer advice and support. There are several things that can help with the symptoms of chemo brain including:

**Treating underlying illness** – your team will check for any conditions that might be making your symptoms worse, such as anaemia, infections, depression or anxiety. All these are treatable, and

treating them may help the symptoms of chemo brain.

**Information** – learning about the condition and how long it usually lasts may help you cope better with symptoms.

**Exercise** – physical exercise is good for the brain. It doesn't have to be too energetic; short, gentle exercise such as walking is enough to improve the symptoms of chemo brain. It also helps to relieve other conditions that make chemo brain worse (for example, depression and anxiety).

**Talking therapy** – your medical team might be able to refer you for specialist help, such as cognitive (talking) therapy.

**Memory clinics** – some centres provide memory clinics offering information, assessment and treatment advice for people affected by chemo brain.

### How long does chemo brain last?

For some people, the effects of chemo brain only last a few weeks. Most people get better between 6 months and 2 years after finishing treatment. However, about a third of people have symptoms that last longer, sometimes for many years.



Keep a diary or use a calendar to write down hospital appointments, birthdays, bills to be paid.

## What can I do to cope with the effects of 'chemo brain'?

- Pace yourself and try to be organised – plan your day, don't take on too much, try to avoid multi-tasking and put important things, like your phone, keys or glasses, in one place every time when you put them down.
- Write things down – keep a diary or use a calendar to write down hospital appointments, birthdays, bills to be paid etc. Use 'to do' lists.
- Reduce stress – relaxation techniques, mindfulness, meditation or yoga can help.
- Keep as physically healthy as possible – try to have a healthy diet and try to get some exercise every day, even if it's just a short walk.
- Keep your mind active by doing crossword puzzles, computer games etc.
- Consider telling your family, friends and work colleagues that your thinking processes have been affected to help them understand how they can support you.

### Does having chemo brain mean I'll get dementia?

To the best of our knowledge, people who have been

affected by chemo brain are no more likely than anybody else to get dementia in later life.

### Are there any medicines to treat chemo brain?

At the moment, there isn't enough scientific evidence to decide which medicines could be helpful for chemo brain. However, research is going on all the time and we are hoping for stronger evidence soon.

With thanks to Jane Gibson, Lymphoma Nurse Clinician, The Christie NHS Foundation Trust, for reviewing this article.





# Community fundraising

**Our Community Fundraising team are here to help groups with their fundraising activities.**

As a community fundraiser this area of fundraising is particularly exciting as we never know what we will be supporting you with next! We work with schools,

sports clubs, amateur dramatic groups, small local businesses - any group that comes together to fundraise. **Whatever activity you plan, we are here to support you!**

## Look out for free themed packs

To help with your fundraising activities, we create themed packs. For example, for Easter there will be a pack full of fun ideas for adults and children. **Look out for them at [www.lymphoma-action.org.uk/Community](http://www.lymphoma-action.org.uk/Community)**

## Did you know?

**Community fundraising contributes between 15 to 20 percent of our annual income? That's why we need you to join in and support us, and have fun at the same time!**



## MEET THE TEAM

Our Community Fundraising team would be delighted to hear from you. Contact:

Amanda in the South East at [a.minett@lymphoma-action.org.uk](mailto:a.minett@lymphoma-action.org.uk)

Jane in the North West at [j.pinder@lymphoma-action.org.uk](mailto:j.pinder@lymphoma-action.org.uk)

Sarah, based in Aylesbury, who supports community groups and businesses across the rest of the UK at [s.thorn@lymphoma-action.org.uk](mailto:s.thorn@lymphoma-action.org.uk)

**Put a date in your diary to hold a fundraising event**

We have lots of activities planned for 2019 and hope that some of them will inspire you to fundraise for us.

## MARCH Quiz month

### Why not hold a charity quiz night?

Our free quiz pack has all you need - six rounds of questions, venue and promotion tips and additional fundraising ideas [www.lymphoma-action.org.uk/Quiz](http://www.lymphoma-action.org.uk/Quiz)

Alternatively, get your local pub involved in the world's biggest pub quiz from 3-7 March 2019. Search PubAid for quizzes and promotional materials.

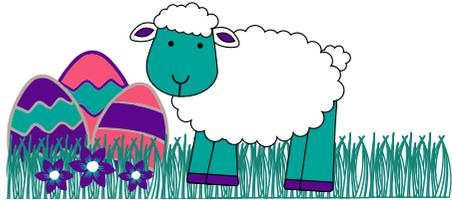


## APRIL Easter egg hunt

### We'd love everyone to get involved in our Easter egg hunt.

Whether it's with school, work or family our easy-to-do Easter egg hunt will get everyone involved. Go to [www.lymphoma-action.org.uk/Easter](http://www.lymphoma-action.org.uk/Easter) to download your free pack.

Also look out for Lori the Lymphoma Action lamb on social media and try to guess where she's been hiding the eggs!



## MAY Spring into Action

### Did you know that May is National Walking Month?

Take the opportunity to get some fresh air and organise your own sponsored walk with a group, or try walking to work for the month.

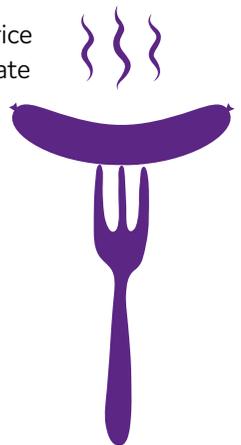
It's **Walk to School Week** 20-24 May, so no excuse for the kids - get them involved too!



## JUNE Lunch for lymphoma

### Enjoy the start of summer with a BBQ, picnic or garden party for your family and friends.

Simply charge a small price or have a raffle and donate the proceeds to Lymphoma Action. For lots of ideas and great recipes, go to our website in May and download your free lunch for lymphoma pack.



Stuart talks about his experience of Hodgkin lymphoma



# A happy ending

**The first time I thought something was wrong was just after my 27th birthday in August 2015, when I had a persistent cough. I have asthma, but the inhaler wasn't helping. Generally I am very fit and work out and cycle, so couldn't understand why I was struggling so much.**

I went to my GP who sent me for an X-ray. When the results came back with queries, further tests were organised. I had a CT and then a PET scan, followed by blood tests. The results of the tests indicated that I needed to see a haematologist. The morning of my appointment I woke up very delirious and didn't know where I was. My

wife called the doctor out and he immediately phoned for an ambulance to take me to hospital.

I had a bone marrow aspiration and they biopsied my neck. A couple of weeks later I was diagnosed with Hodgkin lymphoma.

I initially had six months of chemotherapy and it looked as though I was going into remission from the lymphoma. But two weeks later my young son was lying on me and I felt pain as if I had a trapped nerve. The pain got worse and I started to lose feeling in my right arm

and leg. I went up to A&E and they did a CT scan. A tumour, about the size of a grape, was found in my brain, close to my skull. The doctor was baffled because it is very rare for Hodgkin lymphoma to go to the brain. They also didn't expect it after I reacted so well to the chemotherapy.

I needed surgery to remove the tumour and after the operation they said they were confident that they had removed it all, but felt I needed radiotherapy just to make sure. I needed to have a face mask made and decided I wouldn't let this phase me. I

**I struggled with peripheral neuropathy on my hands and feet, but found ways to help with this.**



had twenty treatments over a four week period and felt I coped well. For a second time, I was given the 'all clear' and went back to work in September 2016. I was looking forward to getting back to 'normal' and went on a two-week holiday. But by October 2016 I was off work again. The lymphoma had come back.

Because it had come back so quickly, my medical team explained that a transplant now needed to be considered. So over the Christmas period of 2016 I was given ICE chemotherapy as conditioning treatment for an autologous stem cell transplant, using my own stem cells. A PET scan showed that the ICE chemotherapy had worked and I had my stem cells harvested in March 2017.

On 24 March, my stem cells were returned to my body. I can honestly say, that the next two weeks were the worst in my life. Despite being in an isolation room with two doors that people needed to go through, I picked up every infection, had diarrhoea and flu and during the two weeks I struggled to eat or drink anything. My medical team explained that once my white cell count came up I would feel better, but at the time I couldn't believe that I would ever be better. I felt like giving up at that point.

But within three days of my white cell count lifting, I could feel a real turn around and started to eat and drink again. Within a week I was able to go home, but that was just the start of my recovery and it took me nearly a year before I was able to return to work.

Once I got out of hospital the first two months were a real struggle. I didn't have any energy or stamina and found it hard to get up the stairs to our flat, or play with my son. Also my immune system was terrible so I found that I picked up anything that was going. I have struggled with peripheral neuropathy (PN) on my hands and feet. I have found ways to help with this, like using thermal socks and using a heat pack on my hands.

I work for a supermarket and had a long phased return to work, which has been helpful. The neuropathy has proven to be one of the biggest challenges, especially when I have to work with chilled food. I also find that I pick up infections such as colds much more quickly, which isn't great when you work with the general public. My company has been excellent and understanding during my whole treatment and recovery. They didn't pressure me to come back and let me recover at my body's pace and were very welcoming when I returned. In March 2019 I will be two years clear and touch wood, everything is good.

”

**In March 2019  
I will be 2 years clear  
and touch wood,  
everything is good.**



**I feel sad that I have  
missed out on so much time  
with my five-year-old son.  
After my treatment we weren't  
sure that we would be able  
to have any other children.  
But I am delighted that on 16  
December 2018, Quinn, our  
beautiful baby daughter  
was born through IVF.**

”

*Stuart*

Dr Anna Ridding discusses

# What is a normal response to a cancer diagnosis?

Picture posed by model

**There is no straightforward answer to 'What is a normal response to a cancer diagnosis?' It depends on so many different factors.**

To start with, you need to consider personality. Whether a person is laidback or anxious, may determine their response to the news.

If a person has always been a worrier, the news is likely to add to their anxiety. Other factors are also important, for example how the news was communicated, what they understand about their type of cancer and the possible outcome or

prognosis. Whether they are due to start treatment straightaway, whether they know others who have had cancer, and experiences they have heard about can also contribute.

Being given a diagnosis of lymphoma is an abnormal situation and **whatever your response is will be normal for you**. There is only one way to deal with your lymphoma, and that is your way.

Around 60% of people experience anxiety after the diagnosis of a serious illness. There are numerous factors at play here including how the diagnosis is perceived as a threat to your identity, personal, family and professional life. Such diagnoses can have an impact on your ability to function, work, and thus finances, and your relationships. That impact may depend on where you are in your life, for example whether you are working, if you have a young family or are taking care of elderly parents. All of these factors (and more!) will affect how you come to terms with a lymphoma diagnosis.

Your anxiety may have increased over the months prior to your diagnosis. You may have suspected another illness, and your lymphoma has been picked up by chance. You may have been ill for some time and it has taken a while to get a diagnosis. You may have had several tests and a biopsy, and you will have had to wait for the results of these. In addition, many people know little about lymphoma, so as well as coming to terms with the disease yourself, you may have to explain what it means to others. There is a lot to take in all at once.

Some people facing a diagnosis of lymphoma are told they will receive no treatment initially, but are placed on active monitoring or watch and wait for some time. This can be anxiety-provoking and relies on an understanding of this approach. There may also be uncertainty about the future, in particular about being able to plan things as you do not know when treatment may start.

.....

### Dr Ridding had some tips and strategies for coping with a diagnosis of lymphoma:

- Consider what is working and what is not working in your life. Consider what you do that makes you more worried – identifying that could be helpful to allow you to try to avoid or reduce it. Don't be afraid to change things if they are not working for you.
  - Although the current situation understandably seems awful, consider all the aspects of your life that are good or 'good enough' – your relationships with your partner, your family, your colleagues.
  - Think of what you have achieved so far and focus on what strengths you have. Focus on how you have overcome and dealt with other difficult life experiences. What do you do that helps you get through? Identify what helps and do more of it – whether it is seeing friends or family, relaxation and mindfulness, support groups, going out, regular exercise – **DO MORE OF IT!**
  - Say how you feel. People in this country are not very good at speaking about their feelings, but it can be enormously helpful for you and those around you. It is OK to express how you feel.
  - We are very good at giving advice, but not so good at receiving it. Think about the advice you might give to a loved one, friend or colleague if they were in your situation. Then try and take heed of this advice.
- .....



**Identify what helps and do more of it!**



**People in the UK are not very good at saying how they feel, but it can be enormously helpful.**

With thanks to Dr Anna Ridding, Principal Clinical Psychologist, Lancashire Teaching Hospitals NHS Foundation Trust.



# A love of Scottish Railway systems and helping others through lymphoma

## Forbes Alexander is just one of the people who has made a difference to the work of Lymphoma Action through his estate.

More of us are making a difference to the charities we love by making sure they receive something after we have died. The reality is that many of our favourite charities couldn't exist without people remembering them in their wills.

It is important not to put off something as important as drafting your will as this is the only way to ensure that the people and causes

close to your heart are remembered and provided for as you would have wished.

We at Lymphoma Action are so grateful to have benefitted from Forbes Alexanders' estate. Forbes was diagnosed with non-Hodgkin lymphoma in the mid-1990s. He was one of the first people in Scotland to be offered a stem cell treatment using his own stem cells.

His brother, Greg, says the treatment was miraculous and goes on to say: 'Once in remission, Forbes returned to work as a town planner and continued to pursue his unusual hobby of researching and visiting Scottish railway signalling systems, a hobby that had led him to publishing a book on the subject in 1990. However, the lymphoma and its treatment took its toll on Forbes and he opted for early retirement.

'Because of his own experience of lymphoma he was passionate about raising awareness of the symptoms of lymphoma, and believed

**Forbes was a remarkable man, he was always cheerful and kept his sense of humour, always laughing!**



that access to information and support was essential. That's why it was so important that after his death, money from his estate went to Lymphoma Action.

'Unfortunately my brother did not manage to update his will to include a gift to Lymphoma Action. So as a family we decided to honour his wish by making the gift from his estate. I guess this is a good reason for urging people to make or update their wills when they can. As a family we are extremely proud that through the work of Lymphoma Action, Forbes is helping alleviate stress and worry for other people with lymphoma.'

**Lymphoma Action are extremely grateful to Forbes and to his family for honouring his wish to make a difference for others affected by lymphoma.**

Each year income received from legacies makes a real difference to the services we can deliver. By leaving a legacy to us, the love and kindness of all our legacy donors lives on through the work we do, ensuring that nobody has to face their lymphoma alone.

### The legal bit

Did you know that there are three main types of gifts you can leave to charity in your will?

### Pecuniary Gift

This is a gift of a fixed sum of money like £500. You can ask your solicitor to 'index link' such gifts if you would like to preserve their value.

### Specific Gift

This is a gift of an item, like jewellery, a house or investment shares.

### Residuary Gift

Once everything has been distributed from your estate and all debts paid, you can leave all or a percentage of the residue to charity.

To leave a legacy you must have a properly written and witnessed will, usually involving a solicitor. Having an up-to-date will is the only way to make sure that your loved ones and any charities or organisations you care about are provided for after your death.

Legacies don't have to be big, whatever the size of your legacy, it will make a difference and help us to be there for someone affected by lymphoma.



### Did you know?

There is lots of information on this for England and Wales on [www.gov.uk](http://www.gov.uk) and to find a solicitor in your area, please visit The Law Society website at [www.lawsociety.org.uk](http://www.lawsociety.org.uk)

# Clinical trials: answering questions about lymphoma

Lymphoma Action were delighted to be involved with the UK lymphoma clinical studies group meeting and gain further insights into the direction of lymphoma in the UK.

**The UK lymphoma clinical studies group is a dynamic and active group of clinicians who work together to develop and deliver a programme of research that helps to drive forward improvements in lymphoma treatment and care.**

The group holds an annual meeting in November, which provides a forum for these experts in the field to give updates on current clinical trials and discuss proposals for new trials.

Lymphoma Action were delighted to be involved with the UK lymphoma clinical studies group meeting and gain further insights into the direction of lymphoma research in the UK.

This report focuses on some of the key themes from the meeting.

## **High-grade non-Hodgkin lymphoma**

### **Diffuse large B-cell lymphoma (DLBCL)**

Much progress is being made in unpicking the biology of diffuse large B-cell lymphoma (DLBCL). Work continues to find out which mutations (changes in the genes) in

lymphoma cells are important in making them cancerous and how this information can be used to target the right treatment to each person's lymphoma.

It is increasingly clear that certain treatments work better for different types of DLBCL. Recent trials testing targeted drugs such as bortezomib and ibrutinib in combination with the standard treatment of R-CHOP chemo-immunotherapy

**Trials testing new treatments are a key part of research for high-grade non-Hodgkin lymphoma, but research studies can provide important insights about these types of lymphoma that can help clinicians target the right treatment to each person.**



(chemotherapy with antibody therapy) have not shown improvements in outcomes for people with DLBCL overall. However, people with DLBCL that has certain mutations could benefit from bortezomib, and people under 65 did much better with the addition of ibrutinib than people over 65. Future clinical trials might explore these differences further.

The results of these trials are also shaping ongoing clinical trials. As adding ibrutinib to R-CHOP caused more side effects for people over 65, then another trial testing a similar drug (acalabrutinib) will no longer recruit people over 65 until we have time to understand these findings better. People over 65 who are currently on the **ACCEPT** trial will be given the option to leave the trial and receive standard treatment or continue and have more preventative treatment against infections. Acalabrutinib may have a better side effect profile than ibrutinib.

Other drugs being tested in DLBCL include lenalidomide,

polatuzumab vedotin and checkpoint inhibitors, which work by helping the immune system recognise and attack the lymphoma.

### T-cell lymphoma

T-cell lymphoma remains challenging to treat, but trials are continuing to test new treatments, particularly for people with relapsed or refractory lymphoma. New treatments under investigation include checkpoint inhibitors, CAR T-cell therapy and two newer drugs that are being tested in combination in the **ROMICAR** trial: romidepsin and carfilzomib.

### Watch this space

The results of the following trials in high-grade NHL are expected to be practice-changing:

- The **IELSG 37 trial** is testing whether radiotherapy can safely be omitted in people with **primary mediastinal large B-cell lymphoma** whose PET scan shows their lymphoma has responded well to standard chemo-immunotherapy. This is an important question as radiotherapy

has the potential to cause serious problems, such as second cancers many years after treatment. However, omitting it might risk the lymphoma not being cleared completely.

- **IELSG 42** was testing a new treatment plan for people with **secondary central nervous system (CNS) lymphoma** – DLBCL in the CNS (brain and spinal cord) as well as in other parts of the body. Lymphoma in the CNS is rare and can be difficult to treat, so the results of this trial could be very important.
- Trials adding polatuzumab vedotin to bendamustine and rituximab for relapsed and refractory **DLBCL** have shown promising results, and longer-term results are awaited. Polatuzumab vedotin comprises an antibody together with a chemotherapy drug, so the antibody can take the drug directly to the lymphoma cells. This kills the lymphoma cells but minimises effects on other parts of the body.

### Observational studies

Trials testing new treatments are a key part of research for high-grade (fast-growing) non-Hodgkin lymphoma (NHL), but research studies can provide important

insights about these types of lymphoma that can help clinicians target the right treatment to each person.

Research studies collect samples and information about each person's lymphoma that can tell researchers more about the biology of the lymphoma cells, which helps them work out how to get rid of the lymphoma.

Ongoing observational studies collecting samples or data from people with mantle cell lymphoma, teenagers and young people with non-Hodgkin lymphoma, DLBCL and skin lymphomas have already produced lots of samples that can further our understanding of these diseases.

### Low-grade non-Hodgkin lymphoma

Several ongoing clinical trials for people with low-grade (slow-growing) non-Hodgkin lymphoma are likely to be practice-changing.

### Follicular lymphoma

**PETReA** is answering

questions about maintenance treatment for follicular lymphoma.

It aims to find out if people who have a good response to their initial treatment need a maintenance antibody treatment, and also to see if intensifying maintenance by adding another drug (lenalidomide) can improve outcomes in those who didn't respond well to their initial treatment.

### Mantle cell lymphoma

Most people diagnosed with mantle cell lymphoma are over 60 and many are less able to tolerate standard treatment. Targeted drugs are transforming the prognosis for older people with mantle cell lymphoma. **ENRICH** is the first trial to test a first-line treatment for mantle cell lymphoma that does not involve chemotherapy. The drugs being tested are rituximab and ibrutinib, and interim results of the study are expected in 2019.

Standard treatment for younger, fitter people with mantle cell lymphoma

includes chemotherapy and a stem cell transplant. The Triangle trial will test whether these people do as well without a transplant, potentially reducing toxicity.

There are distinct types of mantle cell lymphoma that grow slowly (indolent type) or fast (aggressive type), but it is not currently possible to predict how each person's mantle cell lymphoma will behave. The **MCL Biobank study** is collecting samples from people with mantle cell lymphoma with the aim of identifying features that will allow clinicians to determine if a person's mantle cell lymphoma needs treatment straightaway or can be actively monitored for a time. So far, more people have the indolent type than expected, with around 3 in 10 people in the study not needing treatment for more than a year after they were enrolled in the study.

### Waldenström's macroglobulinaemia

Targeted drugs such as ibrutinib are now widely used and very effective for people with Waldenström's macroglobulinaemia. Trials continue to explore whether ibrutinib can be used in combination with other drugs and as a first-line treatment for people with WM.

Several ongoing clinical trials in LGNHL are likely to be practice-changing.

Maintenance treatment, such as rituximab, aims to keep your lymphoma under control for longer by mopping up any lymphoma cells remaining after your main treatment.



A prognostic index uses features of your lymphoma and your individual circumstances to predict how well you are likely to respond to treatment.



## Hodgkin lymphoma

Even when treatment for a type of lymphoma is very successful, questions remain that can only be answered through clinical trials.

Treatment for Hodgkin lymphoma is often very successful but it is still intensive, comprising several chemotherapy drugs and sometimes radiotherapy. These treatments can cause problems later in life (late effects), such as second cancers.

Research continues to try to target radiotherapy only to those who need it, sparing others the possibility of their late effects. Incorporating newer targeted drugs into first-line treatment could increase the number of people who have a good response to their first treatment and do not need radiotherapy. Many of the targeted drugs being tested as part of first-line treatment are already used for people with relapsed or refractory Hodgkin lymphoma, for example brentuximab vedotin and checkpoint inhibitors.

Both ABVD and variations of BEACOPP-type chemotherapy regimens are very effective in treating Hodgkin lymphoma, but both have their pros and cons. ABVD has less effect on fertility and generally fewer side effects than BEACOPP, but BEACOPP regimens are a little more likely to put Hodgkin lymphoma into remission. Questions remain over who benefits from stronger chemotherapy as part of first-line treatment. Clinical trials have shown that people with stage 4 Hodgkin lymphoma, those with high scores on a prognostic index, and those with the most active disease left after their first 2 cycles of treatment do worse than people without these factors. These factors are often considered by clinicians when choosing treatment. Future trials might answer questions over which of these factors is most important and how they can best be used to target intensive treatments to the people who need them.

## Speeding up diagnosis

Many people with Hodgkin lymphoma, particularly young people, visit their GP several times before being referred to hospital. A new test is under investigation that could speed up the process of identifying who needs to be referred. Most people with Hodgkin lymphoma have more TARC (or CCL17) protein in their blood than healthy people. Many people who visit their GP with swollen lymph nodes or other symptoms suggestive of lymphoma like weight loss, fevers or night sweats, have blood tests to see if they have other problems like glandular fever. A sample could also be tested for TARC levels at the same time, and people with positive results might get referred more quickly than usual. A study is planned to further test how effective TARC is in identifying people with Hodgkin lymphoma and how it can be used to speed up diagnosis. The study will recruit people who visit their GPs with swollen lymph nodes or other symptoms suggestive of Hodgkin lymphoma.

**With thanks to Professor Andrew Davies, Professor and Consultant in Medical Oncology, Southampton General Hospital for reviewing this update.**

# Our growing volunteer community



**Our volunteer community has grown over the past year as we've welcomed new volunteers.**

We continue to develop new opportunities for volunteers like organising support group meetings, representing us at events, reviewing our information, helping in our office, running Live your Life workshop and even governing the charity. Thank you to all our amazing volunteers who give their valuable time.

We want volunteering for us to feel inclusive, meaningful and enjoyable. That's why we

launched our volunteer experience survey in June 2018, as part of Volunteers' Week, to gain feedback and insights into how we can improve our volunteer programme. The poster opposite shows the results of that survey.

### **Interested in volunteering?**

Whatever time, skills and experience you have, there are many ways to get involved.

## **Spotlight volunteering opportunity**

### **Support group organiser**

We're looking for volunteers to help provide a safe and confidential space, where anyone in your community affected by lymphoma can benefit from information and mutual support.

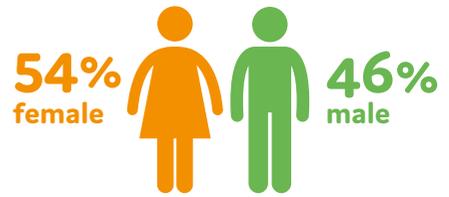
As a Support Group Organiser, you will volunteer closely with the Regional Development Manager and other volunteers, to coordinate and run local meetings. We're specifically looking for volunteers in the South East and London and the North of England. We anticipate this role will involve around 4-6 hours of volunteering a month and would like people who can commit to at least one year.

**For more information and to register your interest, please take a look at [www.lymphoma-action.org.uk/run-a-support-group](http://www.lymphoma-action.org.uk/run-a-support-group)**

**Take a look at the different ways you can get involved in volunteering on our website [www.lymphoma-action.org.uk/volunteering-opportunities](http://www.lymphoma-action.org.uk/volunteering-opportunities).**



# Volunteer Experience Survey 2018



Volunteers are invaluable in helping us achieve our mission to ensure no one faces their lymphoma alone. At Lymphoma Action we are committed to supporting our volunteers to have a meaningful experience with us and we want them to be part of developing the volunteer programme.

We launched our first ever volunteer experience survey during Volunteers' Week in June 2018. The aim of this survey was to gain valuable feedback from our volunteers to provide a baseline understanding of their experience across the organisation and help shape future developments.

The survey was sent to 274 volunteers.

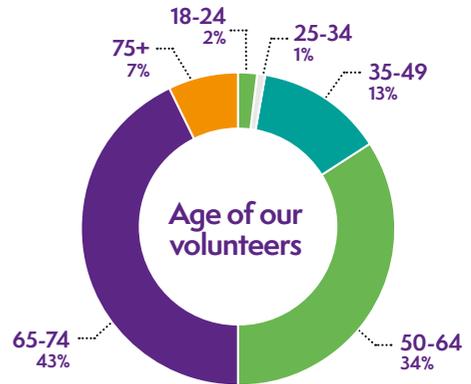
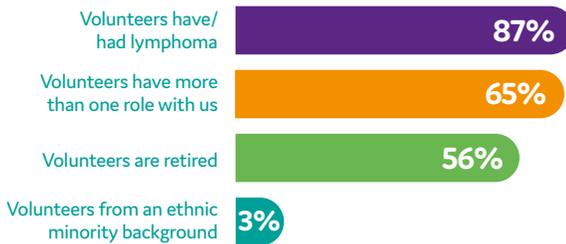


41% volunteer for up to 3-5 years



88% volunteer for up to 5 hours each month

## About our volunteers



## Top three reasons for getting involved:

Believe in the work of Lymphoma Action

Make a difference/raise awareness of lymphoma

Use their existing skills and experience

## The volunteer experience

'It is really helping my self-esteem and sense of purpose to know that I am helping others'



'Meeting people affected by lymphoma and being able to give them tools and knowledge to help them improve their lives'



'I'm happy to be able to give back to Lymphoma Action, in return for the services that it provides and which I so value'

'I feel more confident and informed, and grateful to help others'



## Top three things volunteers have gained:

64%

Feel they've made a difference to people affected by lymphoma

50%

Have a better understanding of lymphoma

44%

Have a deeper connection with Lymphoma Action

- 84% are satisfied or extremely satisfied with their volunteer experience
- 76% have got involved in other opportunities with Lymphoma Action since volunteering e.g. attend events, shared their story, fundraise/donate
- 56% say volunteering has improved their own wellbeing
- 55% say their induction gave them a good understanding about volunteering with Lymphoma Action
- 50% have been given opportunities to connect with other volunteers

## Lymphoma Action Support Groups

- Aylesbury
- Bangor
- Bath
- Bolton
- Brighouse
- Cambridge
- Canterbury
- Cardiff
- Cheltenham
- Chester le Street
- Colchester
- Colne
- Darlington
- Frodsham
- Glasgow
- Guildford
- Ipswich
- Isle of Man
- Kendal
- Lancaster
- Leeds
- Leicester
- London (North West)
- London (North)
- London (North East)
- Macclesfield
- Manchester
- Mold
- Nantwich
- Norwich
- Peterborough
- Plymouth
- Poole
- Portsmouth
- Preston
- Reading
- Southampton
- Southport & Ormskirk
- St Helens
- Teesside
- Truro
- Warwickshire
- Whitehaven
- Wigan
- Wirral



Lymphoma Action closed Facebook support groups:  
 North West  
 South West  
 Yorkshire & North East

For more information about any of our groups, or details of independent groups, please call 0808 808 5555 or 01296 619400, email [information@lymphoma-action.org](mailto:information@lymphoma-action.org), uk or visit our website at [www.lymphoma-action.org.uk/SupportGroups](http://www.lymphoma-action.org.uk/SupportGroups).

# New support groups near you

**Darlington** support group launched on 9 January 2019. It is coordinated by two wonderful volunteers, Terri and Tina, and will be supported by the local clinical nurse specialists.

The latest Yorkshire group was launched in **Brighouse**, with the group meeting in St Josephs Parish Hall, Brighouse. The first meeting was held on Monday 4 February, led by a great new volunteer Michelle. The location was chosen as it will be easily accessible for those attending Huddersfield, Calderdale and Bradford hospitals.

**Bangor** relaunched on 7 February and groups will meet every other month instead of quarterly – meeting on the first Thursday of every other month.

### Moving venues

**Wigan, Mold** and **Bolton** groups are moving venue. Wigan now meets on the last Thursday of the month at Wigan and Leigh hospice. Mold now meets at Parkfield community centre, Mold. Bolton will be moving to the Triangle, Bolton from March.

**Update** – so far 26 people have signed up to take on the **Velocity zip slide** in 2019! We have a mix of people affected by lymphoma, their families and friends and nurses from Whiston hospital on Merseyside. One of our zippers, Ralph from Colne support group is taking on the challenge with his nephew Glen who has also signed up his restaurant, the Eagle & Child, Ramsbottom, to our Purple Plates initiative.

# Zip wire challenge



If you'd like to know more about lymphoma, there are lots of ways to get information and support:

Web, inc Live Chat: [www.lymphoma-action.org.uk](http://www.lymphoma-action.org.uk)  
 Freephone helpline: 0808 808 5555  
 Email: [information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)  
 Facebook: @LymphomaAction  
 Twitter: @LymphomaAction  
 Instagram: @Lymphoma\_Action

## Our helpline can help you emotionally and practically

**If you are worried about a possible diagnosis of lymphoma, have a diagnosis, or know someone with a diagnosis, we understand this can feel scary and overwhelming.**

Our helpline staff, although not medically trained, are knowledgeable, friendly and caring and have a wealth of information at their fingertips. Our service is confidential, can be anonymous if you wish, and is led by what you want to talk about.

We are here to support you through whatever concerns or questions you have, whether you want to talk about symptoms, talk through treatment options, or seek guidance on how you can support someone with a diagnosis. We also take many enquiries about day-to-day practicalities like travelling abroad and generally coping with everyday life.

Talking to someone you know can be difficult because you

don't want to upset them. It can sometimes be helpful to talk to someone you don't know, and express how you are feeling without this worry. We offer emotional support, by way of a listening ear, and even if you don't know what you want to say, you can just call for a chat. Many people find relief just talking through things.

Our helpline is open Monday to Friday 10am to 3pm, and you can contact us on **Freephone 0808 808 5555** or through our Live Chat service via our website. You can leave a message outside opening hours and we'll get back to you. Alternatively you may prefer to email us at **[information@lymphoma-action.org.uk](mailto:information@lymphoma-action.org.uk)**.

Whether you would like more information or would like to talk about how you are feeling, we are here for you. We look forward to you getting in touch.

**If English is not your first language**

**If you would prefer to talk to us in another language you, or someone on your behalf, can call our helpline and ask to speak to us through the interpreting service, Language Line.**



# How can I find out about a trial that may be suitable for me?

**Each person diagnosed with lymphoma will have their case discussed at an MDT meeting. If your doctor feels a trial is an appropriate option they will discuss it with you.**

If it is something you would be interested in finding out more about, then an appointment is made with the trial coordinator, nurse or doctor. Not everyone can take part in a clinical trial as there are only a limited number of trials at any one time and each trial has a limited number of places. But don't be afraid to ask your medical team if there is a trial that may be suitable for you. You can look at the Lymphoma Action TrialsLink site [www.lymphoma-action.org.uk/TrialsLink](http://www.lymphoma-action.org.uk/TrialsLink) for trials currently open for people with lymphoma.

**By entering a trial can I get access to expensive treatments?**

There are many types of trial for lymphoma. Some drugs may already be used in certain types

of lymphoma and are being investigated to see whether it works in other types of lymphoma. Some are looking at reducing the amount of the drug to reduce side effects.

In many trials, everyone has the same treatment, which is often more experimental, so it may allow you access to newer treatments. Do remember though that newer is not always better. In some larger trials people are randomised. This is where you are put into groups that have different treatments. So one group might have standard treatment and the other group might have the new treatment. You are put into a group at random using a computer. You can't choose which group you are in and neither can your doctor or treatment centre. In some trials patients are 'blinded' which means neither you nor your medical team know which treatment you are on.

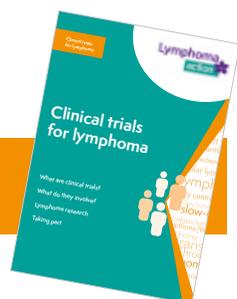


Many people considering a clinical trial worry that they won't get treatment that works and will instead get a dummy treatment – a placebo. It is not ethical to give you a dummy treatment if you need active treatment for your lymphoma and if a trial contains a placebo you will always be informed of that.

There are cases where analysis carried out early finds that the study drug is doing much better. In these cases, people having the alternative drug will be moved to the more effective drug.

There are also a few examples where people on the investigational arm do worse than those on the standard of care arm. In this case, the trial would be stopped. This is rare.

**With thanks to Dr Graham Collins, Haematology consultant and lymphoma lead, Oxford University Hospitals.**



**Our revised *Clinical trials for lymphoma* booklet is now available to order at [www.lymphoma-action.org.uk/Shop](http://www.lymphoma-action.org.uk/Shop)**

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