

lymphoma matters

ISSUE 114 | SUMMER 2019



Lymphoma
action 



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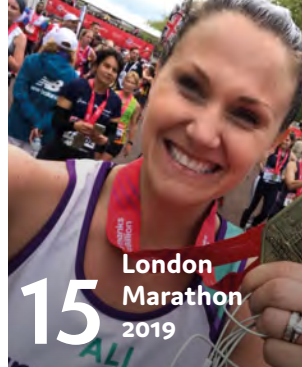
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Views expressed in this publication are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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Get involved

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Professor David Linch

Read about
Professor Linch's
contribution to the
charity on page 5.



We hope you like this
edition of *Lymphoma Matters*.
You can sign up to regularly
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Can you please strip in
the FSC logo here as per
old editions

Farewell from Professor David Linch

**After 28 years as President of Lymphoma Action,
I am retiring from this enjoyable and rewarding role.**

Lymphoma Action began over 30 years ago when a small group of lymphoma patients got together to learn more about their condition. They could find little about lymphoma anywhere, and the few books in the library with anything in were written for medical professionals.

This group decided to set up a helpline so that they could contact each other to share experiences, concerns and any knowledge they could glean. This was the start of Lymphoma Action and that spirit of mutual support and sharing information remains at the heart of everything the charity does.

Over the years, the charity has been at the forefront of developments that have had a major impact in care for people with lymphoma. One that particularly stands out for me has been the introduction of the Lymphoma Clinical Nurse Specialist role. Lymphoma Action was one of the first organisations to recognise the enormous value that lymphoma-specific clinical nurse specialists (CNSs) could bring, and in 2004 embarked on providing three years' funding for up to six nurses in NHS Haematology Units. The importance of this role has now been recognised and CNSs have become a key part of many haematology units.

More recently, Lymphoma Action has got more involved in patient advocacy, ensuring the patient voice is heard at blood cancer groups, within The National Institute for Health and Care Excellence (NICE) submissions and Scottish Medicines Consortium (SMC), and many other areas. They have been instrumental in turning decisions around to ensure the latest drugs are accessible to people with lymphoma.

I have been privileged to have been part of that journey and am retiring knowing that the charity will go from strength to strength.

Professor David Linch



Volunteers at RD:IR commented 'We really enjoyed the experience; good fun and really good for team building. We are grateful to help a small charity in this way.'

Staff and volunteers at Lymphoma Action are thrilled with their updated workspace, which has been transformed thanks to the hard work and generosity of companies who have donated time and resources worth thousands of pounds.

Thrive Homes, Alexander James Contracts, Seviles, Middlesex Flooring, the Aylesbury branch of NatWest and volunteers from RD:IR have all made the update possible, which also includes a new kitchen provided by Howden's.

Middlesex Flooring provided three staff members for five days to fit the generously donated flooring. Seville Developments provided paint and two of their professional painters, who were joined by a team from the Aylesbury branch of NatWest and a six-strong team of volunteers from London investment

company RD:IR, as part of the charity's corporate volunteering programme.

Lymphoma Action Chief Executive Ropinder Gill said: 'Our offices were long overdue a facelift, but spending money on a refurbishment hasn't been a priority. I'm humbled by the lengths people have gone to to give our offices this much-needed overhaul. We're so grateful to our corporate supporters for not only providing the raw materials but also the time, skills and effort to transform the place! It really does make a difference to our workplace.'

Could you or your workplace help?

Lymphoma Action is always on the lookout for more volunteers and corporate support. Individuals and organisations can get involved in a number of ways, and several companies have adopted Lymphoma

Headquarters gets facelift thanks to generosity of volunteers and suppliers

Action as their Charity of the Year, offering sponsorship and team-building opportunities like volunteering and event participation to their staff.

Contact Carly on 01296 619424 or c.benton@lymphoma-action.org.uk if you or your company would like to find out more.



Congratulation to our 2019 prize draw winners:

1st prize £1,000:

A Warren, ticket number 47539

2nd prize £250:

A Davies, ticket number 190741

Prizes of £100:

J Parker, ticket number 103142

D + P Stanley, ticket number 163186

Prizes of £50:

B Hamilton, ticket number 165321

J Wilkinson, ticket number 27755

P Hall, ticket number 36128

J McGrath, ticket number 14196

New from Lymphoma Action

Written by medical writers, approved by experts and reviewed by people affected by lymphoma, our information is revised every 3 years. Here is some of the information that has been written or revised in the last couple of months. Find them at lymphoma-action.org.uk/Publication.

Revised information

- What is lymphoma?
- Staging of lymphoma
- Classical Hodgkin lymphoma
- Skin (cutaneous) lymphoma
- Waldenström's macroglobulinaemia and lymphoplasmacytic lymphoma
- Treatment for lymphoma
- Treatment and remission
- Steroids (in the treatment of lymphoma)
- Dry, sore and itchy skin
- Sore mouth (oral mucositis)
- Late effects of lymphoma treatment
- Exercise
- Managing stress

NEW

We have a new leaflet about leaving a legacy, *Do something wonderful and leave a gift in your Will*. Call 01296 619400 for a copy or find out more at lymphoma-action.org.uk/Legacy



Professor Lynch retires as President

'We would like to thank Professor Lynch for giving his time, expertise and wisdom over the past 28 years. His clinical knowledge and expertise has been generously shared over the years in our wide range of specialist information and publications, articles within this magazine and presentations at conferences.'

David has chaired and led our Medical Advisory Panel which now includes many of the UK's leading consultant haematologists. His opinion, advice, support and position has helped shape some of the services and initiatives we now take for granted and his contribution to Lymphoma Action and people affected by lymphoma has been immense. He will be missed by our staff who have always admired his focus on the needs of his patients and his willingness to help them.'

Ropinder Gill, Lymphoma Action Chief Executive

Lymphoma Action chairs Blood Cancer Alliance

Our Director of Operations, Stephen Scowcroft, has recently been appointed the new Chair of the Blood Cancer Alliance. The Alliance is a group of 12 charities representing people living with blood cancer.

The Blood Cancer Alliance works to improve the experience and outcomes of blood cancer patients through effective engagement with policymakers and policy influencers. They are currently focussing on access to the best treatment, improving provision in health policy and care and providing support and care.

Stephen Scowcroft commented: 'By working together with the Alliance, Lymphoma Action is able to be more involved with significant activities in key policy areas than we would be able to do on our own. With 240,000 people living with over 100 different types of blood cancer, the Blood Cancer Alliance represents a significant group of people with complex needs.'



Lymphoma Community Advisory Board

Lymphoma Action Director of Operations, Stephen Scowcroft, represented the charity at the first European Lymphoma Community Advisory Board (CAB) in Brussels in April.

CABs are groups of patient advocates who use their knowledge and expertise to discuss and advise on the latest developments, challenges and issues related to treatments and procedures under development. They meet with various pharmaceutical organisations, research and regulatory authorities to discuss key areas, collaborate on projects and represent people affected by lymphoma.

By being involved, Lymphoma Action are able to create a louder voice for people affected by lymphoma and influence the research and development pipeline for lymphoma treatments.



Stephen Scowcroft (front row, third from left) with CAB members.

Lymphoma Matters readership survey 2019

We were delighted that over 600 of you completed the readership survey included in the last issue. You can see the results on the page opposite, which give an overview of our readers and the types of lymphoma they are affected by. It also gave a valuable insight into how you view the magazine and the charity too.

9.3/10

Would recommend us to a friend or colleague

For the magazine, it has been helpful to understand the topics you find most interesting. You rated clinical trials as the most interesting topic, followed by personal stories. Knowing this we will make sure that we will keep you updated with latest developments in treatment and continue to share varied stories within the magazine. You also told us that you are interested to hear where your donations go, and we will aim to report on this more effectively.

The survey has been an opportunity to find out what you think about our services. Our information, website, Helpline, Support Groups and Conferences seem to be widely known about, but many of you didn't know about our videos, Live your Life events, our online Community Forum and social media. You also told us that you considered Lymphoma TrialsLink an important service for us to provide, yet it was our least known service. This insight means we can review the promotion of these services to ensure people affected by lymphoma can have access to them. Thank you again for your participation in the survey!

How readers view the magazine



Lymphoma Matters Readership Survey 2019

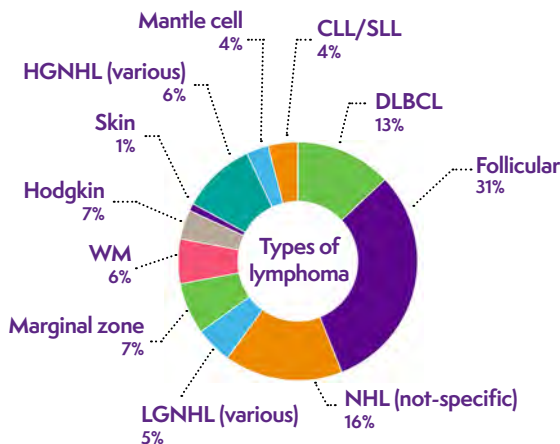
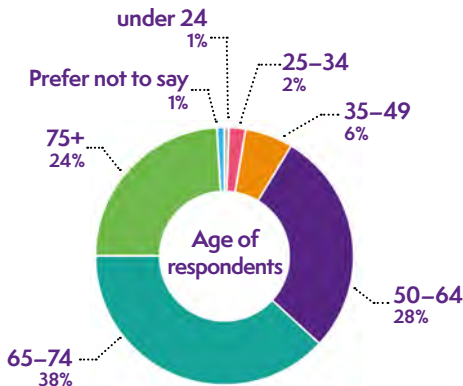
Who responded

613

readers took part in our survey

82%

had a lymphoma diagnosis



70%
are
female



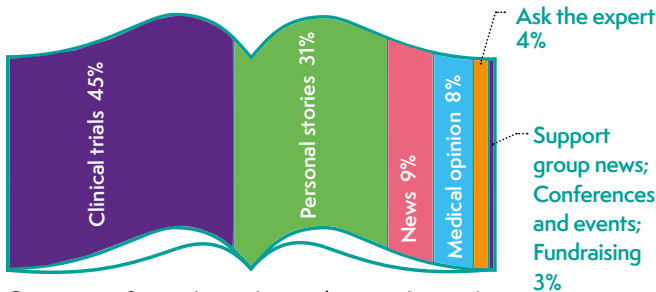
30%
are
male



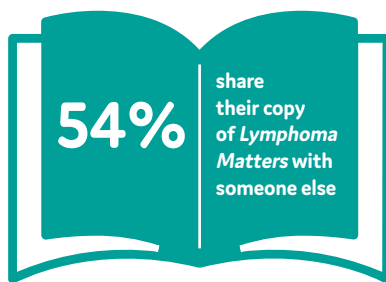
'Your charity has been so helpful to me and my family in understanding blood cancer.'



'Lymphoma Action felt like a lifeline when I was first diagnosed in 2010 and since then they have been simply brilliant!'



Percentage of magazine topics rated as most interesting

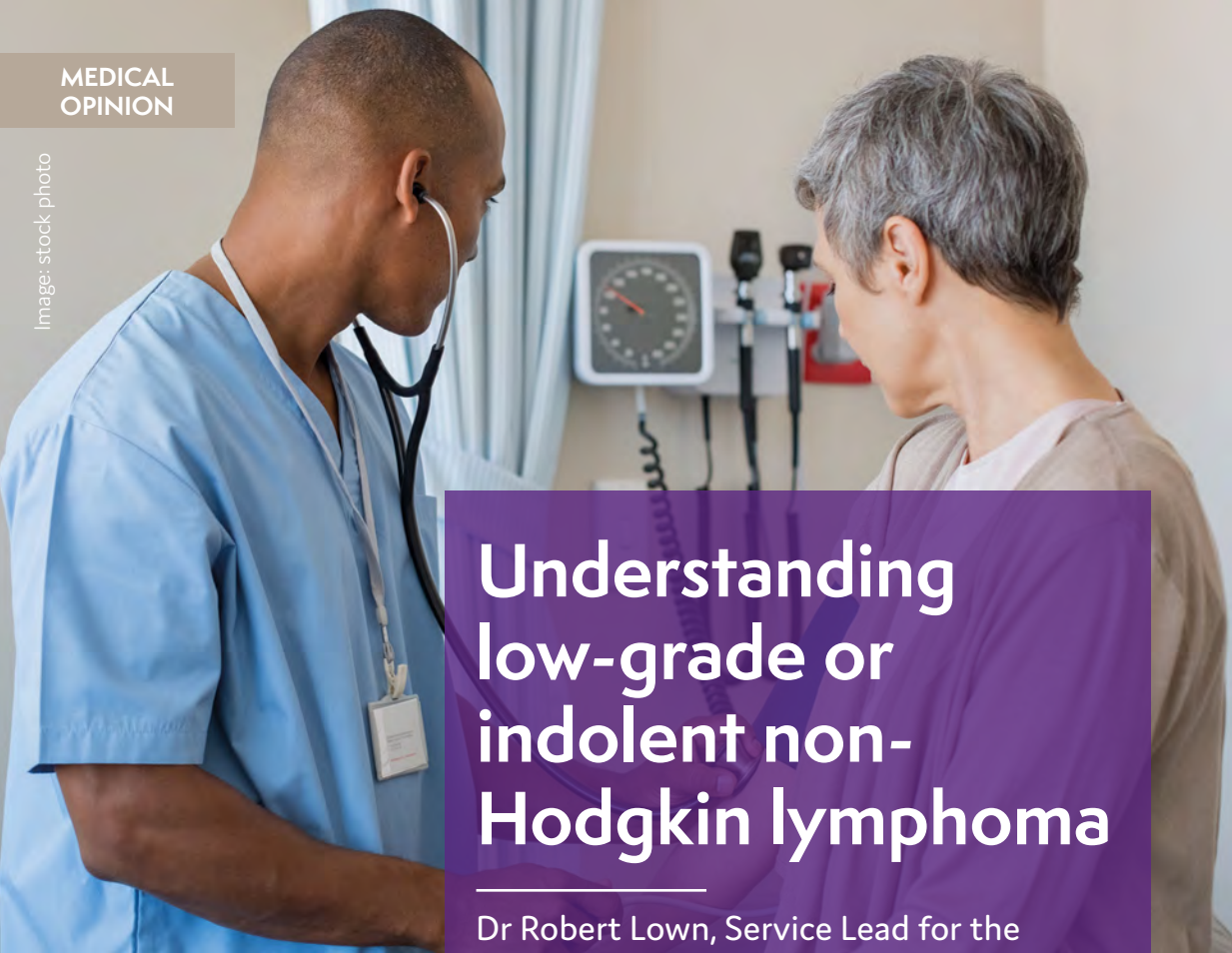


Top Lymphoma Action services:

Services you've used	Services you think are important	Services you didn't know about
1 Booklets or information sheets	Booklets or information sheets	Lymphoma TrialsLink
2 Website	Helpline	Videos
3 Helpline	Support Groups	Live your Life events
4 Support Groups	Website	Online Community Forum
5 Conferences	Lymphoma TrialsLink	Social media

'The magazine has helped me with my diagnosis by bringing other peoples' stories and experiences to me.'





Understanding low-grade or indolent non-Hodgkin lymphoma

Dr Robert Lown, Service Lead for the Southampton Lymphoma Group

'Around half of all non-Hodgkin lymphomas (NHLs) are indolent or slow-growing. Of these, over half are follicular lymphoma.'

Although this article concentrates on follicular lymphoma, the information is also relevant to most other B-cell lymphomas. Most low-grade NHLs diagnosed in the UK are B-cell lymphomas.

Low-grade NHL is far more common in older people, with the majority of diagnoses being in people over 50, and most commonly in people in the 70-85 age group.

Since 1993, the incidence of NHL has been increasing year-on-year. It's not clear why this is the case, but it is probably due to a number of factors including:

- an ageing population
- increased numbers of tests and scans – lymphoma may be picked up when testing for other things. Indeed some people are diagnosed with LGNHL before it is causing them any problems.

One of the biggest challenges facing the

NHS is managing to treat an increasing and ageing population. By 2050, the number of people over the age of 65 will have increased by 50% and the number living over the age of 80 is set to double.

How is indolent lymphoma typically treated?

Indolent or low-grade lymphomas are typically incurable, because some cells do not go through their dividing phase during treatment. Since chemotherapy relies on the

cells dividing to be effective, some disease remains at the end of the treatment. But as the disease typically grows very slowly, it usually takes a long period of time for the cells to divide and a lump to be detected. This process can take 10-15 years or even longer.

A small number of people (about 6%) diagnosed with follicular lymphoma have disease in just one place. This small group can be treated, and potentially cured, with radiotherapy. The cure rate in these cases is about 50%, so around 3% of those diagnosed with follicular lymphoma will have no further evidence of the disease coming back after radiotherapy.

People in another group present with lymphoma in several places, but the disease does not cause any problems. This is called 'asymptomatic'; it is not affecting the person's quality of life and is causing no threat to their health (it's not causing any problems with the brain, heart, kidney, bladder, liver or bone marrow for example). For this group of people, doctors take a watch and wait, or active monitoring, approach.

Whilst we, as clinicians, feel comfortable to do this, we

understand that for many it can be a big challenge.

Although about 85% of people on active monitoring will eventually need treatment for their follicular lymphoma, we do not treat straight away because we know it does not affect overall outcome. The overall survival is the same with follicular lymphoma, whether it's treated immediately or not. As a patient, you will be spared the side effects of treatment and with newer drugs coming along – or research into existing drugs – you may be offered something that is better tolerated.

Rituximab mimics your own immune system and targets the lymphoma cells.

NICE have recommended a short course of rituximab for people who are diagnosed and asymptomatic, as research studies have suggested that using rituximab means you can delay treatment with chemotherapy even longer. Rituximab is generally well tolerated, but it does have a few side effects, such as causing some people to have increased susceptibility to infections.

People with advanced follicular lymphoma that become symptomatic will have a combination of the

antibody rituximab (the R in the regime names) and chemotherapy as standard of care. It is usually six cycles of treatment – R-CHOP, R-bendamustine or R-CVP – followed by rituximab maintenance, usually every 2 months for 2 years. Some people may have a newer version of rituximab, called obinutuzumab.

PET scans are really useful in the management of the disease. Your medical team can note where the disease is and monitor progression. In addition, a negative PET scan after treatment indicates a longer interval before treatment is needed again.

What is the prognosis for advanced stage lymphoma?

Studies have shown that, with modern treatment, 8 out of 10 people treated for advanced follicular lymphoma will still be alive 10 years later. Many people will live far longer than this.

How does rituximab work?

The antibody treatment rituximab has made a big difference to people with lymphoma, and today it forms part of most treatment regimes for follicular lymphoma. Rituximab mimics your own immune system and targets the lymphoma



cells. A newer version has now been produced, called obinutuzumab, which also works well with chemotherapy.

A few drugs on the horizon

Current studies are looking at whether obinutuzumab is better than rituximab for follicular lymphoma, and whether this new drug can be made cost effective. So far, evidence suggests that obinutuzumab keeps people in remission for about 18 months longer, but does not appear to have made a difference to how long people will live. However, NICE have now approved obinutuzumab for use in people with more advanced follicular lymphoma.

If the lymphoma comes back within 2 years, then the lymphoma is not so sensitive to treatment and more

intensive treatments may need to be considered to achieve a longer remission. These might include a stem cell transplant or targeted drugs like idelalisib. Although idelalisib is effective, several side effects have been reported, such as rash and diarrhoea. As a result, a number of trials are being carried out to test newer variations of idelalisib that will have fewer side effects.

Other targeted drugs such as ibrutinib are proving effective in CLL and Waldenström's macroglobulinaemia, but are not as useful for follicular lymphoma.

Another drug being looked at is lenalidomide, which is derived from the thalidomide

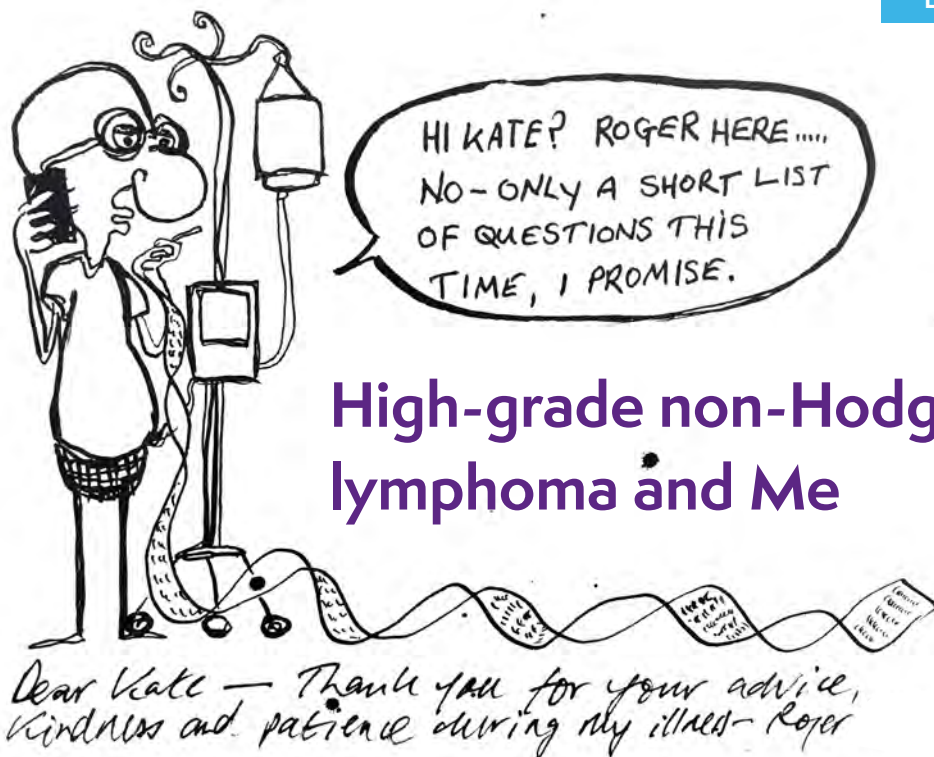
drug that caused deformities in newborns. A study of 1,000 people, of which 500 had lenalidomide and 500 had chemotherapy, showed lenalidomide was just as good but was no better. The good news is that lenalidomide is not too harsh, and has fewer side effects than chemotherapy.

Although it is currently not available on the NHS, within the next 5 years, lenalidomide may become an established treatment for follicular lymphoma.

There has been a lot of talk about CAR T-cell therapy, where cells are engineered to target our own lymphoma cells. Research so far looks promising for follicular lymphoma, but this is still something for the future.'

PET scans are really useful in the treatment of lymphoma.

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



High-grade non-Hodgkin lymphoma and Me

We spoke with Roger in March 2019 and he told us that this was the first week he had felt normal since his lymphoma diagnosis in May 2018. Here Roger shares his story...

'I am 51, married to Anne and have a teenage daughter. I am half-English, half-Dutch and live in Ireland, earning a living as a photographer, podcaster, film maker, writer and marketer.

In May 2018 I was told I had high-grade non-Hodgkin lymphoma. Whilst the words meant very little to me, I understood I had cancer.

After my diagnosis I decided to write a weekly email

newsletter to keep family and friends updated. I used my hobbies of drawing cartoons, writing and storytelling as a way to avoid constantly repeating awful things. But actually, I realise now that not everything related to lymphoma is awful.

Looking back, I'd been tired for a long time, but managed to explain it away. I'd been working hard, often into the evenings and weekends, and had run thousands of kilometres – I'm a seriously keen runner. However, I was running a lot less and was finding it hard to motivate myself. A friend said he'd sponsor my entry into a race, so I signed up for a 58k run, thinking this would motivate me. But I still found it difficult to get out the door, feeling tired before I'd begun.

Over the next 3 months I spent a lot of time in bed. In fact there are statues that moved more than I did during that time!

”

'I'd been looking for an endurance challenge for 2018. I found I was already in it!'

Noticing I was out of breath, I started to realise that I had a problem that was beyond fatigue, so went to my doctor. He told me he could hear that my right lung wasn't taking in air properly and referred me to hospital.

I had a CT scan, which revealed I had a 9cm growth in my mediastinum (which runs down the centre of your chest). Over the next seven days, I had a series of CT scans and X-rays and more needles put into my body than I care to remember. I also had a lumbar puncture and bone marrow biopsy. The results of these tests were to determine my treatment plan. I'd been looking for an endurance challenge for 2018. I found I was already in it!

In preparation for my treatment of R-EPOCH – rituximab with etoposide, prednisolone, Oncovin® (vincristine), cyclophosphamide, hydroxydaunomycin (doxorubicin)–I had a drip port installed in my chest, which meant I wouldn't have needles pinned into me at every turn. I was also given a mobile drip unit which dispenses the drugs, meaning I was tethered to it for the 5 days while I was having my

treatment. I was on steroid tablets and some meds to handle the side effects and generally felt like a walking pharmacy!

The first time I returned home after treatment, I felt adrift from the hospital, the nurses and my medical team. I couldn't sleep, worried about who would watch over me while I slept.

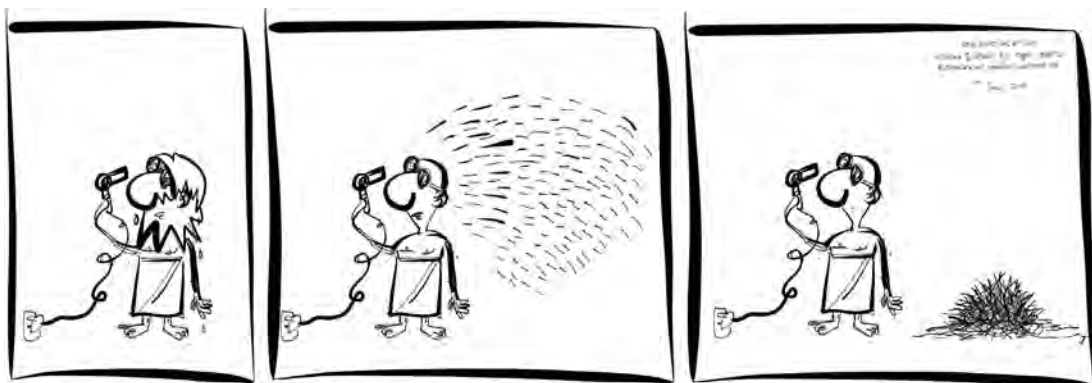
My hair started to fall out. If I touched my face, part of my beard fell out and if I ran my hand through my hair I'd end up dislodging enough hair to make a body wig for a small dog. My daughter shaved it all off. Looking in the mirror, it felt like a stranger was looking back at me. I have to admit that vanity and insecurity made losing my hair harder than it needed to be. Hairy me simply looked better in my eyes and it took me a long time to accept hairless me.

My skin became scaly and wrinkled and my fingernails looked peculiar. They looked like someone had peeled them off and stuck them back on with a minimum of glue. I was also struggling with a strange tingling sensation.

I couldn't sleep, worried about who would watch over me while I slept.



I struggled with my mouth and adopted a strict mouthwash regime to avoid ulcers. Four times a day, I had to brush my teeth and rinse my mouth with an industrial strength chemical that killed off anything that might threaten my oral hygiene. But at the end of treatment my teeth looked stained to me and I was worried about my gums. I wanted to see a dentist, but was told I would have to wait until my white blood cell count had recovered sufficiently, before a dentist poked at my teeth and gums with sharp objects. Normally, not being able to see a dentist would have



filled me with joy. For once, though, I was keen to see a dentist. Cancer changes you in peculiar ways.

Over the 3 and a half months of treatment, I spent a lot of time in bed. In fact, there are statues that moved more than I did during that time! The effects of my inactivity hit home. The feebleness of my legs made it challenging even to walk upstairs. I live at the top of quite a substantial hill. I used to run up it, but after treatment, it may as well have been Everest.

I had to wait 4 weeks after treatment had finished for a PET scan, and then 4 days for the results of the scan. This would tell me if the treatment had been successful. I had been warned that the uncertainty would be a real mental challenge,

especially as I had been cut adrift from the structure of the hospital and my treatment regime. It had become a second home, full of familiar, kind faces.

When 8 October 2018 finally came, the oncologist explained that it was good news. For the next 2 years, I'll have bloods taken and analysed every 3 months, prior to a meeting with my oncologist. After 2 years, I will only need to attend appointments every 6 months, for 3 years. Then I'll be cut loose.

Although the news is good, and my body is slowly mending, 2 weeks after being told the cancer had gone, the emotions

finally came. And they consumed me.

They say that leaving the security of the hospital can feel like a loss. I have said 'Thank you' more in the past few months than in all my life before. And it doesn't feel enough, given how amazing people have been.

I was worried about being labelled. For the rest of my life, I shall be a cancer patient or a cancer survivor. I now realise that for me, rather than trying to avoid the label, it's important to embrace it. It took me a while to do that, but I now realise that I'm calmer for it.'

Roger

The emotions finally came and they consumed me.

I have said 'Thank you' more in the past few months than in all my life before. And it doesn't feel enough, given how amazing people have been.

Taken from Roger's email newsletter. To read the whole story, and see his cartoons, go to www.spierkater.com



ask the expert

At my last appointment my medical team discussed discharging me. I am finding this worrying and wonder whether I can ask not to be discharged?

This is quite difficult to answer because each trust will have their own policies around length of follow-up. Discuss your concerns with your medical team. If there is a specific reason why you are worried, they may be able to reassure you, or refer you to an appropriate team.

You should feel confident that evidence shows that you are the best indicator of whether something is changing in your health, and relapse is rarely picked up at follow-up. Talk to your GP about any concerns you have and they will be able to take things forward for you if you have any health concerns in the future.

Can you see a time when everyone will get targeted therapy?

Treatments are constantly changing. If you go back to before the 1940s there was no chemotherapy and people were treated with radiotherapy alone. Rituximab, for example, has only been in use since the late 1990s, so, if you look at an effective treatment like R-CHOP, this combination is fairly recent. Cellular, or targeted therapy is still very expensive, and at the moment it is hard to say whether it will become cheaper. But it is likely that it, just like rituximab, will become widely used in the future. The real challenge is finding the best targeted therapy for the individual patient. A lot of research is being done through clinical trials to identify targets in a particular patient and therefore to deliver the most appropriate treatment for that target.

I have follicular lymphoma and want to know if there is a difference in prognosis between people who have achieved remission after treatment and those with an indolent lymphoma that has shrunk but not disappeared?

You mention two major categories of response to treatment, namely, a complete response, where all evidence of lymphoma has gone, and a partial response, with some remaining evidence of disease. However, what we know about follicular lymphoma is that

microscopic elements will grow back. If we look at length of remission, then it is typically longer in those who have had a complete remission and shorter for those with partial response. But that is a general comment and individual cases vary.

With thanks to Dr Cathy Burton, Consultant Haematologist at Leeds Teaching Hospitals.

London Marathon

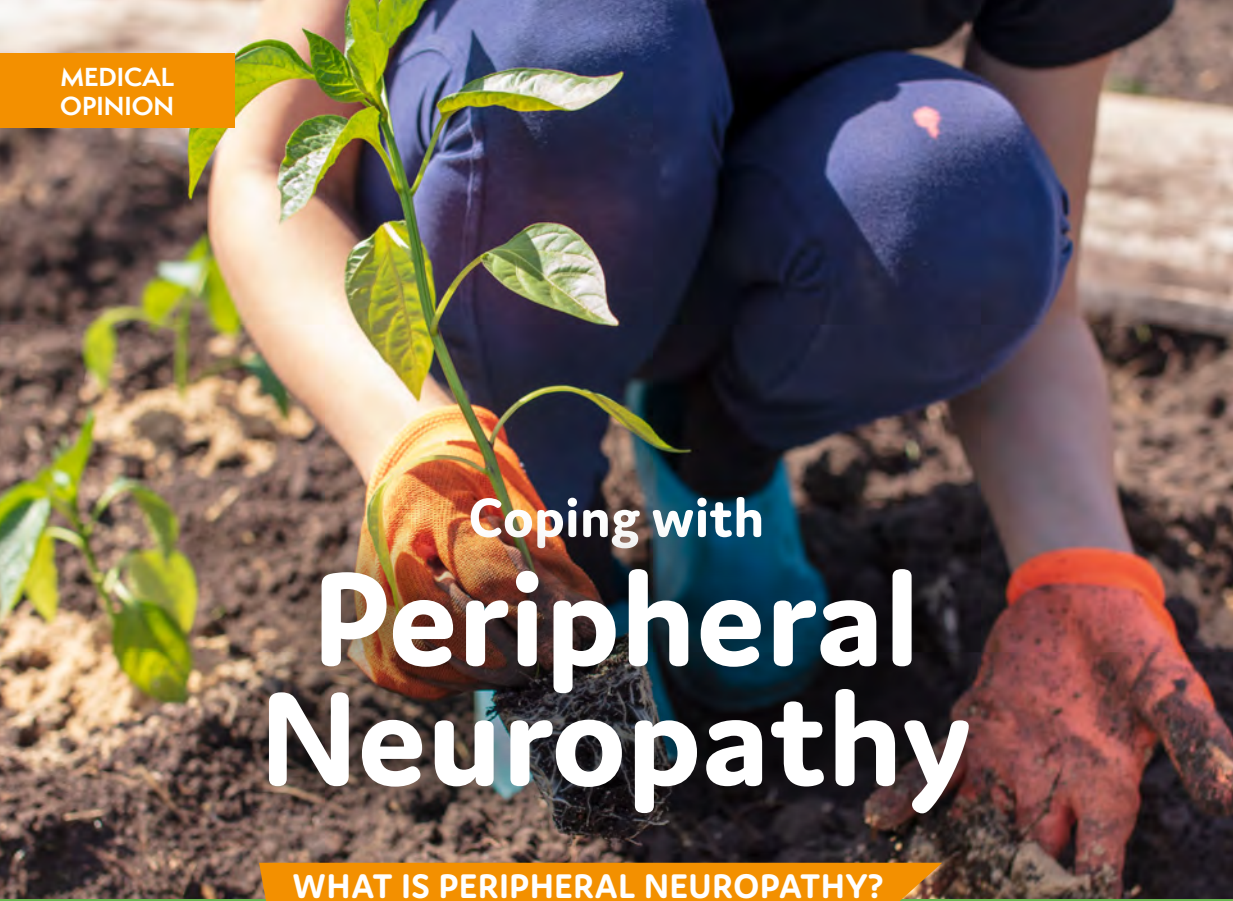
2019

Would you like
to take on a
challenge? Go to
lymphoma-action.org.uk/Challenge

A HUGE thank you to our 37 runners who not only spent months training but also fundraised their hearts out, raising nearly £90,000 to date for Lymphoma Action!

It was lovely to meet so many at our post-race reception and to be able to thank them in person. To our fantastic runners who have committed so much time to support Lymphoma Action, **THANK YOU ALL!**





Coping with Peripheral Neuropathy

WHAT IS PERIPHERAL NEUROPATHY?

Peripheral neuropathy (PN) is temporary or permanent damage to the nerves of the peripheral nervous system.

The nervous system works a bit like a network of electrical wires. The receptors and nerves within it pick up and carry signals and messages between different parts of your body.

PN causes too much or too little nerve activity and disrupts communication between the nerves in your body.

The peripheral nervous system is made up of the:

- **sensory nervous system**, which carries information about the sensations your

skin and joints feel (such as heat, pain and touch), through the spinal cord and to the brain

- **autonomic nervous system**, which carries messages to and from your internal organs (for example about blood pressure, heart rate and the need to urinate)
- **motor nervous system**, which carries messages from the brain, down the spinal cord and to the muscles to make them move.

What are the symptoms?

Symptoms of PN depend on which nerves are affected: sensory, autonomic or motor. Sensory nerves are most commonly affected.

Sensory neuropathy

PN that affects the sensory nervous system is known as 'sensory neuropathy'. The most common symptoms are:

- pins and needles, numbness or a burning sensation, often in the hands or feet
- pain
- increased sensitivity to touch
- heightened or lowered sensitivity to very hot or very cold temperatures
- unexplained sensations (for example, feeling as though you have something in your shoe)
- not being sure about the exact position of your joints when you aren't looking at them.

Symptoms can cause difficulty with fine movement, like doing up buttons, or opening jars. Symptoms that start in your hands and feet might travel further up into your arms or legs if the neuropathy becomes more severe.

Autonomic neuropathy

PN that affects the autonomic nervous system is known as 'autonomic neuropathy'. The most common symptoms are:

- light-headedness or dizziness when you stand up
- constipation
- abdominal bloating
- feeling unable to wait to pass urine
- impotence in men.

Motor neuropathy

PN that affects the motor nervous system is known as 'motor neuropathy'. The most common symptoms are:

- muscle twitches, cramps or pains
- muscle weakness, making carrying

things and climbing stairs difficult

- 'restless legs' (an urge to move your legs).

Why do people with lymphoma get PN?

As a side effect of lymphoma treatment

The most common reason is that some treatments for lymphoma can cause nerve damage. The drugs most likely to cause peripheral neuropathy are:

- vinca alkaloids (a group of chemotherapy drugs) including vincristine (Oncovin®) and vinblastine
- platinum-based drugs, including cisplatin, oxaliplatin and carboplatin
- other drugs such as bortezomib (Velcade®), thalidomide and brentixumab vedotin (Adcetris®).

Chemotherapy-induced peripheral neuropathy (CIPN) tends to affect sensory nerves. You might have only mild symptoms such as tingling in your hands and feet. Severe symptoms are less common.

Symptoms often occur after a few cycles (courses) of chemotherapy. Occasionally, symptoms may get worse or even start only once your treatment has finished. This is sometimes called 'coasting'.

Tell your medical team as soon as possible if you have symptoms of peripheral neuropathy.

For the majority of people, symptoms improve over time, although this can take months or even years. For some people, symptoms continue permanently. There is a higher likelihood of this with more severe symptoms of peripheral neuropathy.



As a symptom of lymphoma

Lymphoma can cause peripheral neuropathy:

- If paraproteins (chemicals produced by some lymphomas), stick to nerves and damage them. This is quite common, particularly in people with Waldenström's macroglobulinaemia.
- If lymphoma cells spread into nerves, compress them or grow around the tiny blood vessels that supply the nerves. This is rare.

Some people in remission wonder if a worsening of symptoms of PN mean their lymphoma is relapsing. This is very unlikely to be the case.

Another condition or illness

Having both lymphoma and another condition that can cause nerve damage (such as diabetes) increases your risk of developing PN. Your medical team consider this when they plan your treatment.

How is PN treated?

At the moment, there is no way to reverse nerve damage. The best course of action is to try to prevent further nerve damage, which is often more successful the earlier nerve damage is found.

Symptoms often start to go away once you finish treatment for lymphoma. It may, however, be weeks or even months before you notice any improvement. For some people, the symptoms never go away completely. With Waldenström's macroglobulinemia, neuropathy often starts to improve once you begin treatment for the lymphoma.

If your treatment causes or worsens PN, your medical team might reduce the dose

or switch you to a different treatment. Nerves often recover if you reduce the dosage or stop taking the drug causing it.

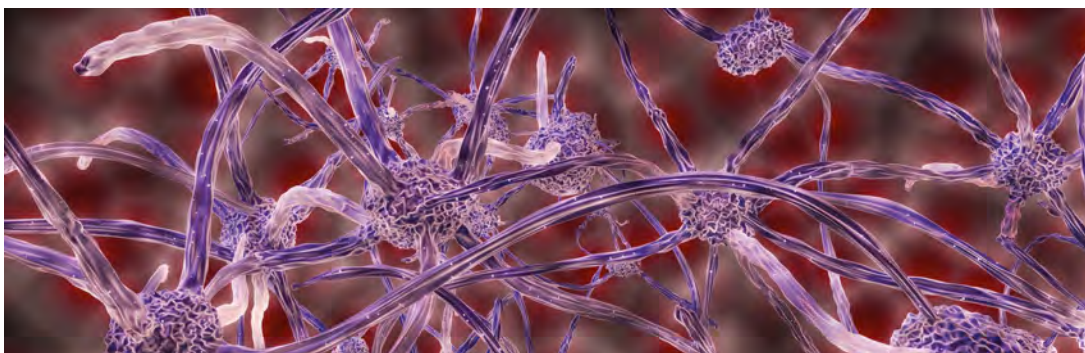
If pain is a symptom, speak to your medical team. In some cases, they might refer you to a pain specialist. You could also be given medication to help such as pain relief drugs, capsaicin cream or lidocaine plasters.

If your neuropathy worsens very quickly, you might be treated with plasmapheresis (plasma exchange) which removes paraproteins from the blood. This is effective in the short-term for some people affected by PN but is not used to treat chemotherapy-induced peripheral neuropathy.

Can I prevent developing PN?

Talk to your medical team about lowering your risk of PN. Tell them if:

- **You have any symptoms of peripheral neuropathy.** They can take this into account when planning your treatment.
- **If your lymphoma relapses and you developed PN during your first course of treatment, your doctors should consider this.** Where possible, they will avoid giving you drugs that could cause or worsen peripheral neuropathy.
- **You might be lacking vitamins from your diet.** Your doctor can check this for you and may prescribe supplements to reduce your risk of developing neuropathy.
- **You drink a lot of alcohol.** To reduce the risk of nerve damage, you might be advised to avoid or lower your alcohol intake while you are having treatment for lymphoma.
- **You are diabetic.** Control your blood sugar levels to reduce the risk of developing PN.



Coping with symptoms

Below are some tips for coping with some symptoms of peripheral neuropathy. Speak to your medical team for advice too.

- Flex and stretch your fingers and toes for a few minutes four times each day.
- Gently massage your fingers and toes.
- Wear gloves and thick socks in cold weather. The cold can worsen symptoms and you may have lowered awareness of temperature, putting you at risk of frostbite.
- Avoid alcohol as it can affect nerve function.
- Ease constipation with a high-fibre diet and drinking plenty of fluids. Laxatives may be helpful, but speak to a pharmacist or your doctor before taking them.

Speak to your doctor if your neuropathy is making day-to-day tasks difficult. They may be able to refer you to another health professional such as a physiotherapist or occupational therapist.

Staying safe

Nerve damage may mean that you don't receive all the signals you otherwise would, including sensations of touch, pain

and temperature. Without these, you may not realise you've hurt yourself.

To prevent injury:

- Wear gloves for gardening and washing up to prevent cuts and scratches.
- Protect your feet by wearing well-fitting, flat or low-heeled shoes. Seek advice from a pharmacist or your GP if you notice redness or signs of rubbing.
- Keep rooms, stairs and passageways well-lit and clutter-free to avoid tripping over.

Avoid burning or scalding:

- Use oven gloves to prevent burns.
- Check the temperature of baths and showers before you get in. Use a thermometer or have someone else check it for you.

Acknowledgements

With thanks to Dr Farquhar-Smith, Consultant in Pain Management and Anaesthetics at The Royal Marsden NHS Foundation Trust for reviewing our recently revised webpage on peripheral neuropathy, which forms the basis for this article.

Nerve damage may mean that you don't receive all the signals, and without these you may not realise you've hurt yourself.





Our first ever

Bridges of London Walk

On the 12 May, a beautiful sunny Sunday, London was a sea of purple. It was fabulous to meet so many of the 340 people that took part on the day - families, several dogs, old colleagues and friends, consultants and CNS's. It was wonderful to hear the stories of why people had joined us on our first Bridges of London Walk.

It was an amazing day - like a great big family day out. The Lymphoma Action team (and hopefully everyone who walked for us) left feeling exhausted but full of joy and inspiration!



The amazing amount of money raised at events this year will help Lymphoma Action deliver:

- booklets to anyone newly diagnosed with lymphoma
- lymphoma-specific events
- our information and support service
- Lymphoma TrialsLink, our clinical trials database.

**More than
£30,000
raised so far!**



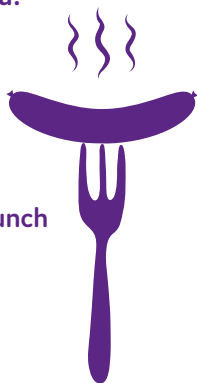
JULY

Lunch for lymphoma

Summer's here, so why not hold a lunch for lymphoma?

It could be a BBQ, picnic or garden party for your family and friends. Simply charge a small donation to support Lymphoma Action.

lymphoma-action.org.uk/Lunch



Collections

This month could you hold a collection in your town, supermarket, station or workplace? We'll provide you with all the support you need including stickers, buckets and balloons.

lymphoma-action.org.uk/Collections

AUGUST

Go 'quackers' with our duck race!

Looking for something fun and different?

Sponsor one of the lymphoma ducks in our duck race on 10 August (see form enclosed with your magazine). The race will be shown over social media so you don't need to live near to take part. First duck over the line wins £100! lymphoma-action.org.uk/DuckRace



SEPTEMBER

27 in 27 challenge

Can you raise £27 in 27 days any way you like? Walk, bake – literally anything! You can begin in August and carry on until October if you like, just pick 27 days and make them count towards raising funds for everyone affected by lymphoma. lymphoma-action.org.uk/27

Pedal4Cancer

Why not get involved in Pedal4Cancer, a 100km national event held on 8 September? Find out more about this London to Cambridge cycle ride at lymphoma-action.org.uk/Pedal4Cancer

OCTOBER

Muddy Mutts dog walk



A great event for all ages and a chance for dogs to do their part!

Join our Muddy Mutts dog walk in Wendover Woods near Aylesbury on 20 October or do your own walk for lymphoma anywhere near you. Dogs will get a special Lymphoma Action bandana and a rosette at the end of their walk. See our website in August for dates and times at lymphoma-action.org.uk/DogWalk



BARD

Breast screening After Radiotherapy Dataset

To find out
more about BARD, go to
christie.nhs.uk/bard or
email
chn-tr.BARD@nhs.net.

Programme for women who had radiotherapy under the age of 36.

Women who have received radiotherapy involving breast tissue when under the age of 36 are at increased risk of developing breast cancer. This includes women who had radiotherapy to treat lymphoma.

National guidelines recommend breast screening starts either 8 years after radiotherapy or at the age of 25, whichever is the latter, and depends on individual doctors referring women who are at risk of breast cancer after radiotherapy.

A project called BARD (Breast screening After Radiotherapy Dataset) has been developed by a team

in Manchester to improve this process. BARD involves collaboration between clinicians, people affected by cancer, NHS England and Public Health England. It comprises a single national list of at-risk women, from which annual screening appointments can be made.

Women will be informed about the structure and intentions of BARD by letter and given an opportunity to opt-out if they so wish. BARD will inform the NHS Breast Screening Programme and GPs of women who received radiotherapy under the age of 36 who require screening.

A BARD research group has

been set up and will be seeing if changes in radiotherapy practice have had an impact on the incidence of breast cancer, and addressing other important questions. Two patient members of the BARD team have said:

'Maybe my story could have been different if it had been post-BARD rather than pre-BARD.' *Natalie*

'Benefits of BARD – structured nationwide approach, with hopeful long term benefits of identifying breast cancer in early stages to provide patients with better diagnosis, in conjunction with a better patient experience.' *Debbie*

It is hoped that BARD will result in more efficient screening and early detection of breast cancer in women who received radiotherapy before the age of 36 and improve the patient experience.

Live your Life workshops are day-long interactive events that are designed for those who have either finished their treatment for lymphoma, or who are on active monitoring.

Live your Life developed with a grant from the National Lottery Community Fund and the first workshops were held in January 2017. Since then they have impacted the lives of close to 1,200 people living with a lymphoma diagnosis.

At the beginning of each Live your Life workshop there's usually an air of suspense. 'Will this be a day of being talked at?' 'Is it worth taking a whole day out of my schedule for?' However, when the facilitator begins with the introduction, describing their experience of lymphoma, the atmosphere in the room instantly changes. Attendees know there will be an open exchange in which everyone understands each other's situation.

Live your Life workshops encourage you to live a life beyond your lymphoma

Living with and beyond lymphoma

Around the country there are powerful and reaffirming conversations about just what a 'new normal' life looks like once treatment for lymphoma is over.



diagnosis, finding your 'new normal'. Once treatment has finished and/or if you've been placed on active monitoring (watch and wait), the expectation is that you'll be really pleased and even euphoric.

However, a more familiar feeling to you, or someone close to you, may be a feeling of anticipated expectancy that simply never arrives. You're in a

vacuum of not knowing where to go or what to do next. You wonder if the physical symptoms you feel are normal, you wonder if the thoughts you're having are unique to you. Live your Life workshops help you manage these feelings and much more.

People leave feeling more hopeful, encouraged and with a wider network of connections.

To see where the next Live your Life workshop is, please visit our website lymphoma-action.org.uk/LYL or call Nika on 01296 619434.





Still trying to acknowledge the fact I have lymphoma

Julia talks about her diagnosis of follicular lymphoma

'I had no idea that anything was wrong with me. I was a regular runner, fit and healthy, or so I thought. So to get a diagnosis last year completely floored me.

I was 47 and had worked in the prison service for 27 years, initially as a prison officer, but more recently in prison education. I am married and have two children; one daughter had recently trained to be a teacher and another was just about to go to university to study midwifery.

I felt this was a time of change and had applied for a new job. My husband and I love to travel and had talked about going to live in Amsterdam. Sadly, that had to go on the back burner as did the new job!

Indigestion had troubled me for 3 years on and off and I found that nothing helped. My GP suggested I have a scan to check that everything was OK.

My husband and I were on our first holiday of the New Year in Lithuania and I was surprised to receive a call while I was away asking me to go in regarding the scan.

The penny hadn't dropped; I thought they were going to tell me the scans were fine.

I went to the appointment on my own, thinking that haematology was just for more blood tests. Instead I was told that the scan had revealed an 11cm x 8cm mass in my abdomen.

In May, after three biopsies, I was diagnosed with follicular lymphoma and six rounds of chemotherapy were planned to shrink the mass.

I was told that when my white cell count was down, I had to be careful to avoid catching anything. It's difficult to avoid germs in places like prison, so I had to take time off during treatment. Sadly all of our trips away had to be cancelled as this also meant I couldn't fly.

I found having chemotherapy wasn't as difficult as I thought. Medications to alleviate symptoms were good and I received great care from my hospital team. My youngest daughter was in Australia while I was having my first treatment and was anxious to be kept updated daily on how I was getting on. Three weeks after starting treatment my hair started to come out in clumps.

The scan at the end of the six treatments showed that the mass had shrunk by less than half, so a further two rounds of chemotherapy were given. I am currently on maintenance rituximab and am interested to see if this shrinks the tumour any more.

I actually feel worse now than when I was having the chemotherapy. Before this, I was never ill, but now I have aches and pains and every twinge I have has made me become paranoid about my health. When I thought about my recovery I didn't necessarily think that I would bounce back into great shape and health straightaway, but I didn't expect to get worse!

I feel like my body, and in part my mind, has been completely devastated by the treatment. I feel that in those weeks of chemo I aged 40 years or more! It's like I went away and came back in the body of a different person I don't recognise when I

look in the mirror. And that's not just about my hair, which is mostly grown back. But it's still early days!

While I was away from work, I didn't have a routine so it was easy to relax and be looked after. I didn't really struggle with the fatigue that I had read so much about. But now I have returned to work, I find I need to plan everything far more than I did before. I am the head of the prison education department and my daughter, who trained as a teacher, works with me. We deliver education to over 8,000 learners a year in a very busy department.

I have attended a couple of Lymphoma Action Support Group meetings local to me. I found them very helpful, with incredibly interesting speakers. I also liked the opportunity to ask questions about things that I either couldn't remember or didn't want to take the consultant's time over. In fact, I have recently volunteered to run the group, as I think it is such a valuable resource.

So over a year on and eight rounds of chemotherapy later, I am still in shock that I have cancer but I am pleased to say we have just taken our first trip abroad and I intend to get back into exercising. I am back working full time and hopeful that I will get many more years before my lymphoma relapses.'

Julia



HIGHLIGHTS FROM THE ASH Conference

The annual American Society of Hematology (ASH) conference took place in December in San Diego, California. In January, haematologists, oncologists and clinical nurse specialists met in London to discuss the implications of the research presented at ASH for clinical practice in the UK.

High-grade NHL

There were many interesting trials in high-grade non-Hodgkin lymphoma in people with diffuse large B-cell lymphoma (DLBCL).

First-line treatment of DLBCL

Several studies focused on maintaining efficacy whilst minimising toxicity in first-line treatment of DLBCL.

- **The FLYER study** looked at first-line treatment for people aged 18 to 60 with a favourable outlook. It found that four cycles of CHOP plus six cycles of rituximab were just as effective as six cycles of R-CHOP.

It concluded that two cycles of chemotherapy can be spared without compromising outcome, with a reduction in toxic events by one-third.

- **The GOYA study** confirmed previous research that there is no added benefit to having eight cycles of R-CHOP compared to six cycles of R-CHOP for people with DLBCL who have not been treated before. People experienced fewer side effects with six cycles of treatment.

Other studies looked at using the molecular fingerprint of the lymphoma to predict

treatment outcomes or to target treatment.

- A large study found that people with a genetic mutation in a gene called *MYC* have a poorer outlook than people who do not have this mutation. This includes people with double-hit or triple-hit lymphoma.
- **The HOVON trial** also looked at people with aggressive B-cell lymphomas with a *MYC* mutation. In this population, adding lenalidomide (a drug that reduces the activity of the *MYC* gene) to R-CHOP showed promising efficacy and a favourable side effect profile.
- **The CAVALLI study** found that for people with a mutation in a gene called *BCL2*, adding the *BCL2*-inhibitor venetoclax to R-CHOP shows promising early results.

The FLYER results are immediately practice-changing in a carefully selected patient population. Prof Andy Davies, Consultant Oncologist, University of Southampton



• The PHOENIX study

showed that in people under 60 with DLBCL who have a genetic profile known as 'non-germinal centre' (non-GCB), adding ibrutinib (a cell signal blocker) to R-CHOP was more effective than R-CHOP on its own. It was not effective in over 65s because a higher rate of side effects led to more dose reductions.

Relapsed or refractory DLBCL

There were also some interesting developments in the treatment of DLBCL that is refractory or has relapsed after treatment.

- Updated results from a phase 2 trial showed that adding polatuzumab vedotin to bendamustine and rituximab improved survival in people with relapsed or refractory DLBCL who were not suitable for a stem cell transplant. Polatuzumab vedotin is an antibody–drug conjugate that targets cells that make a protein called CD79b.
- A phase 1 trial studied a regimen called VICER (venetoclax, ifosfamide, carboplatin, etoposide and rituximab) in people with relapsed or refractory DLBCL. VICER showed a

high response rate but side effects such as neutropenia were common.

- A phase 2 trial studied a combination of drugs called iR² (ibrutinib, lenalidomide [Revlimid®] and rituximab) in people with relapsed or refractory non-GCB DLBCL. iR² showed promising activity with a manageable safety profile. Analysis of the trial is ongoing.
- Data from the USA reported outcomes of CAR T-cell therapy in the 'real world' similar to those in clinical trials, even though half the people who received CAR T-cell therapy would not have met clinical trial entry criteria.

New treatments for DLBCL

- A phase 1 trial described the first human tests of a T-cell bispecific antibody (TCB) called RG6026. TCBs can attach to two targets. RG6026 attaches to a protein called CD20 on B cells and a protein called CD3 on T cells. It showed promising activity in relapsed or refractory DLBCL. Although it can cause serious side effects, it is an exciting potential

treatment for people with limited treatment options and may represent an 'off-the-shelf' alternative to CAR T-cell therapy. Further research is ongoing.

Low-grade NHL

The post-ASH presentation focused on the management of follicular lymphoma.

Predictors of response

- The GALLIUM study looked at whether a measure called 'minimal residual disease' (MRD) could be used to predict who is likely to relapse after first-line chemo-immunotherapy and maintenance therapy for follicular lymphoma. MRD was assessed by genetic analysis of bone

marrow samples at

the end of the initial treatment and during maintenance therapy with either rituximab or obinutuzumab.

Most people who became MRD negative after initial treatment or during early maintenance had a durable response. However, people who did not had a high chance of experiencing early progression. This could be used to direct treatment choices.

Other methods of identifying people who might relapse or progress early include PET/CT scans and gene expression profiling.

First-line treatment of follicular lymphoma

Lenalidomide plus rituximab (R²) is a potential first-line treatment option for follicular lymphoma. It appears to have similar (but not superior) outcomes to existing chemo-immunotherapy regimens with a different side effect profile. Long-term data from a phase 2 trial showed that R² produced durable responses. After 7 years of follow-up, most patients remained in remission.

Advanced-stage follicular lymphoma

Bendamustine plus rituximab is a common first-line treatment for people with advanced follicular lymphoma. A study presented at ASH showed that people who do not experience disease progression within 24 months of treatment (POD24) have excellent outcomes. However, people who progress within 24 months have much poorer outcomes. Most of these people have transformed lymphoma.

Relapsed follicular lymphoma

Several promising chemotherapy-free agents are emerging for people with relapsed follicular lymphoma.

- Drugs currently in clinical trials include R², umbralisib (a cell signal blocker) plus obinutuzumab, lenalidomide plus obinutuzumab, and obinutuzumab plus CHOP.
- Radio-immunotherapy with betalutin (a radioactive particle joined to an antibody that targets a protein called CD37 on non-Hodgkin lymphoma cells) has shown promising activity and trials are ongoing.
- 5F9, the first in a new class of drugs called 'macrophage immune checkpoint inhibitors' has shown anti-tumour activity in animal studies.

Hodgkin lymphoma

Developments in Hodgkin lymphoma centred on measures used to predict response to treatment, and on long-term outcomes.

Early-stage Hodgkin lymphoma

Standard treatment for early-stage favourable Hodgkin lymphoma is two to four cycles of ABVD followed by radiotherapy (depending on risk factors). The HD16 trial looked at whether a PET scan after two cycles can be used to predict outcomes and adjust treatment intensity if necessary.

In people with a negative PET scan, omitting radiotherapy resulted in poorer outcomes. People with a positive PET scan were more likely to experience disease progression and should be considered for more intensive treatment.

Advanced-stage Hodgkin lymphoma

People with advanced Hodgkin lymphoma who have a positive PET scan after two cycles of ABVD have poorer outcomes than those with a negative PET scan

The SWOG study looked at whether 'response-adapted' therapy, where people with a positive PET scan switched to more intensive treatment with BEACOPPesc, could improve outcomes. The study had excellent results after 2 years. The 5 year follow-up data were presented at ASH.

- Overall survival at 5 years was high.

We need better ways to identify those who are going to do well with existing treatments. Those who are likely to progress can require different treatment approaches. Prof Tim Illidge, Professor of Targeted Therapy and Oncology, the Christie Hospital, Manchester



People with Hodgkin lymphoma can be discharged from follow up after 2 years. Routine blood tests are of no utility. Dr Wendy Osborne, Consultant Haematologist, Freeman Hospital, Newcastle



- However, nearly 1 in 4 people who had a negative PET scan after two cycles and did not have escalated treatment experienced relapse.
- In the patients who had a positive PET scan after two cycles, around 1 in 3 experienced relapse. The more intensive treatment was associated with a high rate of second cancers.

This study confirms the need for better predictive information upfront in order to target intensive treatment to people who need it and minimise toxicity and late effects for people who do not.

Management of older patients

People over 60 do not do as well as younger people on standard Hodgkin lymphoma treatments, mainly due to a higher rate of side effects.

- A German and Nordic trial found that a regimen called B-CAP (brentuximab vedotin, cyclophosphamide, doxorubicin and prednisolone) showed promising response rates and was well tolerated in

older people with newly diagnosed advanced-stage Hodgkin lymphoma. Most people were able to tolerate all cycles of treatment without any dose reductions.

Long-term follow-up

- A study in Denmark, Norway and Sweden followed over 2,500 young people (18 to 49) with Hodgkin lymphoma treated with present-day regimens. In people who had not progressed or relapsed 2 years after treatment, the 5-year risk of relapse was less than 5%. This confirms that 2 years is an appropriate length of follow-up for people with Hodgkin lymphoma. Routine blood tests are not helpful in detecting relapse.

Chronic lymphocytic leukaemia (CLL)

Some of the research presented at ASH has the potential to change recommended treatment for people with chronic lymphocytic leukaemia/small lymphocytic lymphoma (CLL/SLL).

First-line treatment for CLL

Several studies reported at ASH looked at ibrutinib-based treatment options. Ibrutinib is a cell signal blocker.

- **The iLLUMINATE trial** found that ibrutinib plus obinutuzumab was more effective than chlorambucil (a chemotherapy drug) plus obinutuzumab in people with CLL/SLL who were over 65 or had high-risk disease. This represents a well tolerated, chemotherapy-free treatment option.
- Another trial compared ibrutinib monotherapy, ibrutinib plus rituximab or bendamustine plus rituximab in people over 65. Ibrutinib, on its own or with rituximab, was more effective than bendamustine plus rituximab.
- Ibrutinib plus rituximab was also compared with FCR (fludarabine, cyclophosphamide and rituximab) in people under 70. It was more effective than FCR and had a favourable side effect profile. Importantly, people treated with the ibrutinib combination experienced longer responses and had an overall survival

In view of the recent advances in the treatment of CLL, the British Society of Haematology guidelines on the management of CLL will very soon need updating again.

Professor Anna Schuh, Associate Professor and Director for Molecular Diagnostics and Consultant Haematologist, University of Oxford



advantage, although the numbers of participants analysed so far is small.

These findings have practice-changing implications and establish ibrutinib-based therapy as the most effective first-line therapy for most, if not all, patients with CLL. However, for all these studies, the follow-up period was short, and longer-term data might reveal that particular subgroups of patients do better on conventional chemo-immunotherapy.

Treatment for relapsed or refractory CLL

Relapsed or refractory CLL is usually treated with more chemo-immunotherapy or with ibrutinib, either on its own or in combination with rituximab. Venetoclax is mainly used indefinitely in people who have stopped responding to ibrutinib.

Some studies presented at ASH looked at a fixed duration of venetoclax over 2 years, in combination with other agents.

- **The Bloodwise TAP Clarity study** looked at combining fixed-duration venetoclax with ibrutinib in people with relapsed or refractory CLL. The combination had a high response rate, was well tolerated and induced MRD negative responses in most patients. MRD negativity is a very good marker for the efficacy of a particular therapy.
- **The MURANO trial** found that fixed-duration venetoclax plus rituximab was more effective than bendamustine plus rituximab in people who had had at least one previous treatment for

CLL. The venetoclax combination was generally well tolerated, although neutropenia was common. Treatment continued for up to 2 years. For most people, the response was maintained after treatment stopped.

- A laboratory study found that relapse during venetoclax treatment is associated with a specific genetic mutation in the *BCL2* gene. This might be used in future to identify patients at risk of relapse or to develop drugs that are even more effective than venetoclax.

New treatments for CLL

A phase 1/2 trial tested the safety and activity of umbralisib (a cell signal blocker) in combination with ublituximab (an antibody therapy) and pembrolizumab (a checkpoint inhibitor) in relapsed or refractory CLL. The study included people with CLL that has transformed to a more aggressive type (Richter's transformation).

Early results were promising. The combination had a high response rate, including in some patients with Richter's transformation. Treatment was well tolerated.

Acknowledgements

With thanks to Professor Andy Davies, Consultant Oncologist, University of Southampton, Professor Tim Illidge, Professor of Targeted Therapy and Oncology, the Christie Hospital, Manchester, Dr Wendy Osborne, Consultant Haematologist, Freeman Hospital, Newcastle and Professor Anna Schuh, Associate Professor and Director for Molecular Diagnostics and Consultant Haematologist, University of Oxford, for reviewing this summary.



There is still work to do, but the change so far has been really positive and leaves plenty of scope for the future.

To find out more about what we have achieved this year, and read our 2018 annual report and account, go to lymphoma-action.org.uk/Accounts

Lymphoma Action – one year on

After 20 years of being called the Lymphoma Association, we became Lymphoma Action on 18 April 2018. We feel the word 'Action' conveys our aspiration to take action on behalf of everyone affected by lymphoma. Along with a new name, we introduced a new look and a new website.

'I think the new name is great! It has a bit of "oomph" and is much more dynamic than the old one.'

Our new website, comprising over 800 published pages, was designed to be more patient-focussed and easier to navigate. From feedback, and

the steady increase of users, it seems that we are well on the way to achieving this.

Not everything changed though. We have retained our core services and continue to provide the same high quality information, support and care. We also retained the periwinkle as part of our branding, as the Madagascar periwinkle has cancer-fighting

properties. It is used in the drugs vinblastine and vincristine, which are used in the treatment of Hodgkin lymphoma.

'Your clear and helpful booklets were of immense value to me when my husband was diagnosed and when his treatment was over and I was struggling to find holiday insurance your helpline came to the rescue. Tremendous support, always there when I need it - thank you.'

Over the last year we have introduced a new website, recruited more volunteers and represented more people affected by lymphoma.



Lymphoma Action Support Groups

Aylesbury
Bangor
Bath
Bolton
Brighouse
Cambridge
Canterbury
Cardiff
Cheltenham
Chester le Street
Colchester
Colne
Darlington
Frodsham
Glasgow
Guildford

NEW Harrogate

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

Support Groups

Over 45
Support
Groups

Focus on Peterborough Support Group

Attendees of the Peterborough Support Group explain why they feel support groups are so valuable.

Caroline is one of two haematology CNSs in Peterborough and was involved in setting up the Lymphoma Action Peterborough Support Group in 2014. She told us:

'I was approached by Lymphoma Action, but at first I was a little hesitant as I was the only nurse specialist, and was concerned that I would not be able to devote the time needed to coordinate a group. But Lymphoma Action reassured me that they would help set up the group and support me in establishing it.

I see the support group as being an invaluable resource for people affected by lymphoma, wherever they are on their pathway. Some people wish to have regular contact with others, some dip in and out when they feel they need to, or when there is something on that they particularly want to be involved with.

I enjoy being part of the group, both from a professional and personal point of view. There's something for everyone with formal talks from speakers and informal social meetings. I also like to be available if someone wants to ask me something they didn't feel they could ask in their clinical appointment.'



I would encourage anyone to come along and 'give it a go' – you may get more out of it than you think!

Caroline, Haematology CNS
(pictured with organiser Maureen)



Lymphoma Action Closed Facebook Support Groups:

North West
South West
Yorkshire & North East

For more information call 0808 808 5555, email information@lymphoma-action.org.uk or visit our website at lymphoma-action.org.uk/SupportGroups.

The value of support groups – from Peterborough Support Group attendees

Go to our website to find
a support group near you, or
call 0800 808 5555.

If you're interested in volunteering
to organise a support group
near you, please register your
interest on our website.

For me, the most
enjoyable meeting is
when we have a speaker
who can broaden my
knowledge. *Kathie*

I benefit greatly from
the lovely colleagues who
are so supportive and
caring and have been such
a help to me. *Pat R*

I find it rewarding making people
aware of lymphoma and being
there to support, not just the
person with lymphoma, but their
family and friends also. *Maureen,
Support Group Organiser*

I feel I get a chance
at the meetings to pass
on my experiences and
learn from others. *Maggie*

I joined for support and
I wanted to give back
the help it has given me.
Kathleen

I still worry about my
cancer at times... there
is always someone to
talk to and share similar
experiences with. *Risé*

I joined the group hoping
that meeting other people
with my illness would
help me in my recovery. It
certainly has. *Rodney*

When my lymphoma
worsened, I turned to the
group. I was scared and felt
isolated, but found going to
the group so helpful. It's a
wonderful lifeline. *Jayne*

It is good to meet up
with people in the
same position, as they
understand what you
have been through. *Joyce*

I was looking for some
support and it was reassuring
to talk to other people who
had lymphoma, many of
whom had lived with it for
many years. *Pat C*

Initially I went along for support so that I
didn't feel quite so alone. Eight years on and I
feel I can contribute to the group, having been
through various treatments. *Audrey*

I thought it would be
worth going along to
meet others and gain
more of an understanding
about lymphoma. *Paul*



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
Helpline (freephone): 0808 808 5555
Email: information@lymphoma-action.org.uk

Facebook: @LymphomaAction
Twitter: @LymphomaAction
Instagram: @Lymphoma_Action

GDPR – at a glance one year on

The new European general data protection regulations (GDPR) came into force on 25 May 2018. The regulations were introduced to change the way organisations, including charities, hold data and contact their supporters or customers.



GDPR protects us all by ensuring that organisations only store and use our data with our consent, or where there is a 'legitimate interest'.

Here is an outline of what GDPR means for you and how it has affected us a year on.

GDPR took time and resource to implement, and we tried to get as many positive 'opt ins' as we could. Although the number of people we could contact initially shrank by 62%, we have since built this back up, especially as guidance was issued on 'legitimate interest'.

Some forms of communication and processing of data always require us to have your explicit 'opted in' consent, such as email.

Your right to say 'no' to postal marketing materials takes priority over our need under 'legitimate interest' to write to you. This means that we have to make it easy for you to say 'no' to our communications.

We have to make sure our privacy notice sets out what you can expect to happen

with your data when we communicate with you. You can find this on our website and at the end of our email. We don't do third-party fundraising such as door to door canvassing or telephone fundraising through agencies and we keep your data safe.

A positive result of GDPR is that the charity's resources are better spent communicating with those who are happy to be communicated with.

Last but not least: please contact us via fundraising@lymphoma-action.org.uk if you want to change how we communicate with you or would rather not receive our postal communications.

We hope that those affected by lymphoma see the value in our services and why their support is so important.

Read our privacy policy at lymphoma-action.org.uk/Privacy

Did you know?

We cannot communicate with you by email unless you have actively 'opted in'. You can do this at lymphoma-action.org.uk/SignUp

September is Blood Cancer Awareness Month



Lymphoma Action will be using Blood Cancer Awareness Month to raise awareness of lymphoma. Every 27 minutes in the UK someone receives a lymphoma diagnosis. We need to reach more people affected by lymphoma and the only way we can do that is with help from you.

We want as many people as possible to get involved in many different ways including:

- Sharing our social media posts throughout the month and especially on Sunday 15 September, World Lymphoma Awareness Day.

- Put up one of our special posters anywhere you can.
- Begin your 27 in 27 fundraising campaign and raise £27 in 27 days.
- Run an awareness stall in a local hospital or shopping centre.

With your help we can reach the 19,500 people who will receive a diagnosis in the coming 12 months. Help us let them know they are not alone and that we are here for them.

For resources and further information please contact fundraising@lymphoma-action.org.uk or visit lymphoma-action.org.uk/Campaigning

COULD YOU

**RAISE £27
IN 27 DAYS?**

AUGUST - OCTOBER

Every 27 minutes a friend or loved one is diagnosed with lymphoma in the UK.

27 in 27 is an easy way to help us provide much needed support so that no one has to face lymphoma alone.

There are so many ways to raise £27 in 27 days:

- Walk, cycle, run or swim 27 miles over 27 days
- Give up chocolate/wine/beer/meat/caffeine for 27 days
- Try 27 different types of fruit or vegetable, or cook 27 different recipes over 27 days.

Find out more and sign up



www.lymphoma-action.org.uk/27



01296 619419



fundraising@lymphoma-action.org.uk

