Your blood tests
Insight into pathology
Clinical trials update
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 to 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.

Contents

04 Latest news
News and developments

08 Ask the expert
Insight into pathology

16 Fundraising
Our calendar of events

18 Medical opinion
Research into follicular lymphoma

20 Personal story
Dwayne shares his experience of skin lymphoma

34 Support groups
Kevin explains the benefits of attending a group

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

If you would like to make a donation towards our work please visit lymphoma-action.org.uk/Donate or call 01296 619419.
Working in collaboration

I hope you enjoy this latest edition of *Lymphoma Matters*. As well as our medical writers, *Lymphoma Matters* only comes together because of the stories and time given by our supporters, by healthcare professionals and by those willing to share their experiences (and their photos!) – thank you.

So much of what we do is in collaboration with others, whether it’s getting behind the *One Cancer Voice* manifesto with other charities, working as part of the Blood Cancer Alliance to make the change we need for the future, or being an active member of the global Lymphoma Coalition. There is real strength in numbers when it comes to influencing decisions that will impact those affected by lymphoma.

And being collaborative is one of our five new values. Building on the brand refresh, we have been looking at what we do and how we work. We have developed new values and created a long-term strategy that reflects our ambitions for the future. We hope this resonates with you, and appreciate your ongoing support as we aim to reach even more people affected by lymphoma.

You can read about our strategy, how our work impacts people and about those at the heart of it all online at lymphoma-action.org.uk/AboutUs

Our new values

**Focused** We are dedicated to the needs of those affected by lymphoma.

**Empowering** We build confidence to make change happen.

**Trusted** We use our expertise to deliver quality services.

**Innovative** We look to a better future for people affected by lymphoma.

**Collaborative** We are inclusive and value our partnerships.
136,000 people in the UK are living with chronic cancer

A recent study from Macmillan Cancer Support and Public Health England’s National Cancer Registration and Analysis Service (NCRAS) has found that there are 136,000 people in the UK living with chronic cancer.

Chronic cancer is cancer that is treatable, but not curable, where treatment aims to control the cancer or slow its progression, relieve symptoms, and improve quality of life. Some types of lymphoma fall into this category, with treatment aiming to control the lymphoma and send it into partial remission – with several different treatments over the course of living with the condition.

Worryingly, the research showed that more than 3 in 4 people with chronic cancer are not getting the support they need – whether that is emotional, physical or financial. Living with chronic cancer can be challenging, but with the right support and treatment, people with chronic cancer should be able to live their lives as fully as possible.

One Cancer Voice: A manifesto for people living with cancer

In November, in collaboration with 28 charities, we launched a manifesto for people living with cancer calling on the Government to improve prevention, diagnosis, treatment and care.

As the population living with cancer grows, we must ensure that people are not just surviving longer, but living well too. The #OneCancerVoice manifesto makes recommendations covering six key areas:

- Putting the right staff in place
- Diagnosing cancer earlier
- Ensuring people living with cancer have access to the appropriate treatment and psychological support
- Supporting people living with cancer beyond their treatment
- Preserving the UK’s status as a world-leader in cancer research
- Preventing people from developing cancer.

With 1 in 2 people in the UK diagnosed with cancer at some point in their lifetime, this could improve millions of lives and touch every family in the country.
New information now available

Written by medical writers, approved by experts and reviewed by people affected by lymphoma, our health information is updated every 3 years.

We have recently revised three of our books:

• Hodgkin lymphoma
• Autologous stem cell transplant (using your own stem cells)
• Young person’s guide to lymphoma, which includes quotes from young people affected by lymphoma, like Georgia who is featured on our magazine cover.

Order your free copy online at lymphoma-action.org.uk/Shop or download from our website at lymphoma-action.org.uk/Books

We have also revised our webpages on:

• marginal zone lymphomas (MALT, nodal and splenic)
• common chemotherapy regimens for lymphoma
• lymphoma during pregnancy
• what happens if lymphoma relapses.

Did you know?

You can download PDFs of our health information under the left-hand side menu of each page – or, if you are looking on a phone or tablet, at the bottom of the page.

You can find a list of all of our our downloadable PDFs at lymphoma-action.org.uk/Books
Join our fabulous FAMILY EVENT

Bridges of London Walk – Sunday 7 June

Suitable for all ages and abilities, our Bridges of London walk is back. This walk is all about you – its Your Walk, Your Way – and will take place on Sunday 7 June.

Walking from Vauxhall Park to Tower Bridge by criss-crossing over 11 bridges is one of the best ways to see the capital. You will have plenty of time to take in all the sights and you may want to stop and enjoy lunch by the Thames.

As this event is arranged completely by us, all the money you raise goes towards supporting people affected by lymphoma. It will be rewarding, fun, absolutely achievable, and we would love to welcome you to Team Lymphoma.

Adults £10, family (2 adults + 2 children) £25, young people aged 4 to 16 £5, children under 3 free.

All we ask is that you try to raise £100 in sponsorship and we will support you in your fundraising. All adult walkers receive a T-shirt and medal. Children also receive a medal. Small T-shirts are available to purchase in advance for £6.50.

Book your place on this fun event at lymphoma-action.org.uk/Bridges

Book your place at lymphoma-action.org.uk/Bridges
Does the diagnosis of lymphoma always rely on a biopsy?

It’s very unusual for a patient’s first diagnosis of lymphoma not to require a biopsy, but there are some lymphomas that ‘leak’ a lot of cells into the blood and those can be diagnosed from blood tests.

A pathologist is a doctor who looks at laboratory samples under a microscope and does specialised tests on them to help make a diagnosis.

Chronic lymphocytic leukaemia is a classic example of a lymphoma that shows up in the blood. When the same disease stays put in lymph nodes (we don’t yet know why it does this), it’s called ‘small lymphocytic lymphoma’ – and that would need a biopsy for diagnosis.

Hairy cell leukaemia and splenic marginal zone lymphoma are another two examples of lymphomas that have a lot of cells in the blood stream and may not need a biopsy for diagnosis.

Sometimes a lymphoma is diagnosed coincidentally when surgery is being undertaken to treat another condition, such as a suspected cancer in the lung, breast or bowel. Those patients will not usually need any additional biopsies.

When the diagnosis is known and disease becomes more extensive, or relapses after treatment, a biopsy is often not needed for confirmation, as imaging studies (MRI, PET and CT scans, for example)
Preparing tissue samples is a complex process that takes time.

It is very unusual for a patient's first diagnosis of lymphoma not to require a biopsy.

Preparing tissue samples is a complex process that takes time. In the future, ‘liquid biopsy’ techniques such as single cell and cell-free tumour DNA testing may become commonplace in these circumstances.

How is it decided what type of biopsy is required?
It’s often a matter of what is practical in a particular place or at a particular time. It also depends to some extent on how likely a diagnosis of lymphoma seems in any particular patient. There are many infectious and inflammatory causes of lymph node enlargement that initially mimic lymphoma but will resolve on their own over time. We want to sample those in the least invasive way possible – usually by a fine-needle aspirate, with local anaesthetic – to obtain a relatively small number of cells to assess, for reassurance. This approach is also very efficient for detecting cancers other than lymphoma and getting those patients quickly onto the right care pathways.

From a pathologist’s point of view, thinking about making a diagnosis of lymphoma, I want the patient to have undergone a biopsy procedure that’s the least invasive, but which provides plenty of tissue for me to make a full diagnosis without having to ask for a further sample.

Fine-needle aspiration can usually be done very quickly and the patient doesn’t need a general anaesthetic. Aspirates are good samples for seeing whether there is, or is not, lymphoma, but they often don’t allow us to tell exactly what type of lymphoma is present. For that, a needle biopsy (to obtain a small solid core of tissue) is often the next quickest and easiest procedure to do. Most lymphomas can be diagnosed fully from these samples as long as they are of good quality.

However, there is often no left-over tissue for research from needle biopsy cores, and some lymphomas are very difficult to diagnose without being able to examine larger amounts of tissue. So, sometimes a whole lymph node must be taken out; this requires the patient to have a general anaesthetic and undergo a (usually small) surgical procedure.

In general, we need more tissue to diagnose lymphomas than many other types of cancer.
lymphomas than many other types of cancer because, in addition to looking at ‘standard’ histological sections under a microscope, we need to do additional tests such as immunostaining and molecular tests to reach a full diagnosis.

**Do you look at the sample alone or view scan images and blood tests as well?**
Whenever we can access them, we look at all these different tests together, to inform the assessment we make of the tissue sample. When we aren’t able to do this, we do our best to discuss the results with the haematologists, radiologists and other clinicians involved in the patient’s care, to put the full picture together while we are assessing the tissue. When even that isn’t possible, we join the team of doctors, nurses, scientists and therapists who come together at MDT meetings to make sure that all the different pieces of the jigsaw puzzle fit together as they should, so that the diagnosis is correct.

**Why does it take about 2 weeks to get the biopsy results?**
You can rest assured that if a very aggressive lymphoma, like Burkitt lymphoma, is suspected, every effort will be made to fast-track every step in the laboratory to get the result ready and back to your oncologist or haematologist within 48 hours. Unfortunately, we can’t do this for every sample.

The reason why things normally take longer is because the tissue sample first needs to ‘fix’ in its formalin preservative. It then needs to be processed into a wax block, then have microscope sections cut and stained, and have extra tests done such as immunostains and molecular tests. Formalin fixing takes up to 24 hours, depending on the size of the tissue sample. For tiny pieces it can be as little as 8 hours. Processing into one or more wax blocks takes another 24 hours and getting the various stains done typically takes another 24 to 48 hours. Adding molecular tests may add a further week because they are not done in the same lab. They are expensive too, so they’re batched to keep the costs manageable. However, we rarely wait for molecular tests before making our diagnosis – the results of those tests refine rather than determine our assessment.

When samples are sent from a smaller local hospital to one of the large regional lymphoma laboratories, results can take an extra 2 to 3 days while the material is in transit. We all work hard to keep this to a minimum but it is a necessary price to pay for access to the more extensive resources and expertise at the regional centres.

As a pathologist, once the sections are stained and ready (thanks to my excellent biomedical scientist colleagues in the lab, who are the experts at doing all of that), I then typically need an hour or two to assess all the slides and information to formulate my report. A complicated diagnosis may take half a day or even more. For speed, I like to write my own reports directly onto the hospital computer system but, in some hospitals, reports are dictated and then typed up before being approved and authorised. You can see how the time needed for all of this adds up.

**Are biopsies ever sent elsewhere (other treatment centres or overseas, for example)?**
Yes. In the NHS in England, biopsy specimens known or suspected to have lymphoma are all sent to be assessed by experts based in large regional pathology centres. Apart from the specialist knowledge...
In the NHS in England, biopsy specimens known or suspected to have lymphoma are all sent to be assessed by experts based in large regional pathology centres.

of the pathologists at these centres, the larger size of these laboratories means that they have access to a wider range of immunostains and genetic tests than is available at smaller hospitals. Similar, although less formal, referral arrangements also operate throughout the NHS in Scotland, Wales and Northern Ireland.

If a lymph node sample is difficult to interpret for some reason, and particularly if it seems to show something rare that the local or regional pathologist may not have seen many times, it may be sent for assessment by an individual with very specific expertise in diagnosing a particular type of lymphoma. Some expertise of this sort is only available overseas, for example in the USA or Hong Kong, because that’s where the individual highly specialist pathologist happens to work. Sometimes there is particular expertise in one country (for example, Hodgkin lymphoma in Germany) because there has been a long history of clinical trials being based there.

Another reason why biopsy samples are sometimes sent elsewhere, including overseas, is for research as part of a clinical trial. This is something you should expect, as the patient, to be asked to give your consent for (or, if you wish, to withhold consent) as part of the discussions around your consenting to take part in the trial.

Do you discuss the results at MDT meetings?
Yes. Every lymphoma diagnosis is discussed at the multidisciplinary team (MDT) meeting by a member of the pathology team. This may be the pathologist who has actually reported on the sample, or a colleague with whom they have discussed the findings in preparation for the MDT meeting. In general, for diagnosing lymphomas, we work in teams of three or more pathologists, so that we can report samples with a minimum of delay, quality-assure one another’s work and occasionally take a holiday! Most pathologists find the MDT meetings are some of the most rewarding parts of their work; we love being able to ‘see’ the patient through the discussion that takes place among the different clinicians who are present and we value being part of the clinical team.

With thanks to Bridget Wilkins, Consultant Haematopathologist, St Thomas’ Hospital, London and Royal Hampshire County Hospital, Winchester for answering these questions.
I have been married to Yvonne for 27 years and we have two sons; one is 21 and at university and the other is 24 and has recently started working as a nurse. I am an IT Project Manager.

On the first day of a break with my family I developed, what felt like, a bad throat infection. The lymph nodes in my neck became very enlarged, and I thought I must have picked up a strange infection on a business trip. I was given intravenous antibiotics.

Once home, I was referred to an ENT consultant. After excluding some possible causes, the ENT consultant wanted to continue to monitor me, as my lymph nodes were still a bit swollen.

After a couple of MRI scans showed no change, a needle biopsy was arranged. The needle biopsy wasn’t conclusive, so I had two lymph nodes removed from my neck under general anaesthetic in early January 2018. In the days after the lymph node removal my neck was getting bigger and bigger. I thought I had developed an infection in the wound, but it was the remaining lymph nodes in my neck continuing to swell. I was getting increasingly worried, and I found it difficult not knowing what the problem was.

Even with all this medical focus on my lymph nodes, strangely, I did not think I had lymphoma. Both my elder brother and dad died of non-Hodgkin lymphoma; my brother in 1999 and my dad in 2001. So I thought I knew the symptoms of lymphoma, and my symptoms were different. Having said that, I was also certain that of all the things I did not want it to be, number one was lymphoma.

After a difficult month of waiting and worrying, in
February 2018 I was diagnosed with angioimmunoblastic T-cell lymphoma, a type of high-grade non-Hodgkin lymphoma, and the same lymphoma my dad had.

More tests followed including a PET scan, bone marrow tests and more blood tests. I was told that I would be treated with six cycles of CHOP chemotherapy, and then if I was in remission, I would be given a stem cell transplant.

We wanted to be open about it, and wanted our sons to know first. We went to see each of them in turn. They knew I had been unwell for a while, and had been off work, so knew it was something serious. But I was impressed by how caring and mature they were, and was reassured that they were as OK as they could be with the news. My mum would also have to go through the non-Hodgkin lymphoma experience of an immediate family member for a third time; maybe that’s unique. Yvonne, my sons and my mum were amazingly resilient, and this helped me.

I now felt able to let others know, and found telling family and friends very helpful as everyone was very supportive. Small gifts and regular phone calls made me realise they cared – perhaps more than I had known before. Although I had already been off work for several weeks, I was now able to give them a clearer picture of what my diagnosis would mean work-wise.

I began treatment at the end of February 2018 with CHOP chemotherapy. At the beginning of the second cycle I lost most of my hair. I woke up one morning with loads of it on the pillow, and then had a shower and lost most of the rest, so decided to shave off what was left. It was a bit weird and I was self-conscious for a few days, but people were quite positive about my new look, so I began to feel OK about it.

The six chemotherapy treatments were in 3-week cycles. By the end of the second cycle I knew the pattern:

Week 1 – low appetite and feeling sick, and sometimes being sick
Week 2 – feeling better than week 1 but aching back and hips
Week 3 – feeling normal(ish).

By the end of the second cycle I could see a bit of improvement. My lymph node swelling was reducing, and I was tolerating the chemo.
My brother and dad had lots of trouble with infections during treatment, so I was worried about picking up infections. I was careful about hand hygiene and avoiding anyone who was unwell.

I had another PET scan and was told the chemotherapy was working. It was positive news, and given my family history, I felt very emotional.

I had my last dose of chemotherapy the day the 2018 World Cup started. I am a big football fan and being able to watch every game was certainly a plus. I made the most of it and really enjoyed watching them all!

My treatment plan had always been to have an autologous stem cell transplant using my own stem cells. A PET scan scheduled for about 6 weeks after the last dose of chemotherapy would tell if the chemotherapy had been successful. Although I was apprehensive about having the stem cell transplant, I was even more worried that the chemotherapy hadn’t fully done its job.

The days leading up to the PET scan were difficult. We decided to go away as a family for a short break, and hoped it was a chance to relax. But it was a mistake, and all it did was spread the anxiety between us.

I eventually had the PET scan, and it was the best news; the chemotherapy had worked. I had my stem cells harvested in late July 2018 in readiness for the stem cell transplant the next month.

By the time of the transplant I was feeling better and stronger. I was in no doubt that the transplant was the right course of action, but I was very anxious about it, and knew it would be physically challenging. My eldest son is a nurse, and during his degree course he spent time in a stem cell transplant unit, so we had some idea of what was involved.

I had LEAM chemotherapy, which is a high-dose chemotherapy called ‘conditioning’ every day for 6 days, and then my stem cells were given back to me. I felt progressively worse as the days of treatment went by. I developed mucositis (ulcers in my mouth, throat and digestive tract) which made eating difficult, and I also had very bad diarrhoea. Over the next 3 weeks I lost a stone and a half.

As expected, my blood counts dropped, and I found the days when I was neutropenic frightening. I was again worried about picking up an infection. I was in hospital for almost 3 weeks feeling progressively worse, but suddenly my blood counts began to recover, and I began to feel a little better.
Work were really helpful and we realised that the old normal was not going to be the new normal. At least not for now.

I was allowed home fairly soon after that, even though my blood counts were still low. To be honest, I didn’t feel ready to go home. I was still nervous about picking up infections and was still struggling with diarrhoea. The mucositis had all but gone, and I was eating again, but my sense of taste was weird. I couldn’t taste anything sweet and lots of savoury things tasted very different.

My energy levels were low, but I tried to get outside and walk a bit, even in the early days at home. I began to feel better, but it was slow, and not every day was better than the last. There were times I felt like I was going backwards and my energy levels weren’t getting higher. But I was getting better and I just needed to be patient.

I began a phased return to work at the beginning of January 2019, and initially worked from home. It was good to be getting back to normal, and I was keen to do so as quickly as possible. I thought it would bring closure to my lymphoma experience. By the end of March, I was back to working 5 days a week, commuting to London occasionally.

By early May I realised I was struggling. I felt very tired, still had some digestive problems, and also could not achieve the closure to my lymphoma experience I wanted. I spoke to a psychological nurse who helped me to think about my life after lymphoma. I needed to adjust my work life balance.

Work were really helpful and I think between us we realised that the old normal was not going to be the new normal. At least not for now. I am now working less, and Yvonne and I are enjoying this new phase of life together, that at the beginning we thought we might not have. Whilst I’m not sure this is the forever normal, it’s normal for now.

Owen’s family history of lymphoma
For most types of lymphoma, there are no clear causes. Lymphoma is not inherited – it is not passed from parent to child. However, your risk of developing lymphoma is slightly higher if you have a close relative (parent, brother or sister, or child) who has had lymphoma. This increased risk is usually not linked to a particular gene. Research suggests the increased risk may be caused by inheriting several polymorphisms (variants of a gene that can affect the way the gene works) that all contribute a small increase in risk. These polymorphisms are often in genes of the immune system.

Owen is currently participating in a genetic project and it is hoped that such studies will help understanding in the future.
**MARCH**

**Quiz month**

Switch on your brains because this is quiz month!

Download our pack of top tips on holding a quiz, including six rounds of quiz questions from lymphoma-action.org.uk/Quiz

Alternatively, get your local pub involved and join the world’s biggest pub quiz across the UK from 8-12 March 2020. There is no charge to take part, but it is a great way to raise money for Lymphoma Action. PubAid will supply you with the quizzes and promotional material. Go to worldsbiggestquiz.pubaid.com for more details.

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**APRIL**

**Easter fun**

We are leaping with joy and egg-static it’s Easter!

Help get the country treasure hunting by holding Easter Egg Hunts. Our Egg Hunt pack includes pictures of eggs, which you can cut out and hide in your garden or perhaps even at work around your office! Children will also enjoy our LEAP for lymphoma where we are encouraging them to be sponsored to bunny leap for lymphoma.

To get your Egg Hunt pack or your LEAP for lymphoma pack – including bunny ears! – visit lymphoma-action.org.uk/Easter

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**MAY**

**All about food**

May is all about food. Get your friends and family together and hold a Lunch for lymphoma.

You can host a lunch at home and charge a small ticket price, then hold a raffle on the day. BBQs, picnics and evening dinner parties count too! Alternatively you could ask a local restaurant to support you with a set menu, where you can add a little extra on the ticket price and raise some additional funds. For lots of ideas and some great recipes go to our website and download your free Lunch for lymphoma pack: lymphoma-action.org.uk/Lunch

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**JUNE**

**Bridges and teddies**

Join in with our Bridges of London walk on Sunday 7 June – full details on page 7.

As it’s June, why not hold a teddy bears picnic? This is a lovely way to involve children and is very easy to organise with your family, school or nursery. Just ask children to bring their favourite teddy and provide some snacks and games. For your fundraising pack, please visit lymphoma-action.org.uk/Teddies
The Lymphoma Action Spring Prize Draw is a great opportunity for you to make a difference to our frontline services!

Caroline reached out to our support services after receiving her own lymphoma diagnosis: ‘When I contacted Lymphoma Action they were so supportive, and they were the first people that I had a conversation with where I wasn’t completely terrified. The Buddy that they found for me was the first person who gave me hope and now I want to do the same for others in a similar position.’

Caroline received a diagnosis of stage 4 follicular lymphoma just as she turned 40. She has now been in remission for 13 years, and knows from personal experience just how important our services are in helping people feel informed, encouraged and supported during their treatment and beyond.

Help us to keep our front line services running by taking part in our Lymphoma Action Spring Prize Draw. Every ticket bought helps us to continue our work in making sure that no one faces lymphoma alone. To find out more, call the Fundraising Team on 01296 619419 or email fundraising@lymphoma-action.org.uk

Spring is the perfect time to sow periwinkle seeds. Ours are only £1.50 a packet and are sure to brighten up your garden. The Madagascar periwinkle (Catharanthus roseus) is used to produce two chemotherapy drugs – vinblastine and vincristine. Once your seeds have grown we would love to see your photos, so please share them on social media at #LymphomaMatters.

Periwinkle seeds and pin badges are perfect for wedding favours at lymphoma-action.org.uk/Shop

IT’S SPRING

Do something wonderful

Legacies are vital to us. Please remember Lymphoma Action in your will.

Find out more about legacies at lymphoma-action.org.uk/Legacy
FOLLICULAR LYMPHOMA

A journey from prognostic factors to risk-adapted therapies

Professor Stefano Luminari, Professor of Oncology at the University of Modena and Reggio Emilia in Italy, gave a fascinating talk at the 49th Annual Trials Meeting. He compared his research into follicular lymphoma with a holiday in his home town of Modena.

Choose your destination
When you’re going on holiday, you choose your destination carefully and make sure the planning, expense and time involved is going to be worthwhile. Similarly, when addressing a scientific question, you need to choose your area of research carefully.

In this case, the subject is risk-adapted therapy for follicular lymphoma. The question to ask is: is follicular lymphoma suitable for risk-adapted therapy?

The results of previous trials suggest that it is: follicular lymphoma is a heterogeneous (diverse, composed of different parts) condition and several factors have been identified that influence treatment outcomes. There does seem to be a clear difference between people who are at high risk of relapse or progression and those who have a longer-lasting response to initial therapy.

Select your means of transport
The next step in your journey is to choose your transport and plan your route.

In terms of response-adapted treatment in follicular lymphoma, this means deciding how to define ‘high risk’ and how to measure response to treatment.

Several scoring systems, such as FLIPI and PRIMA-PI, use clinical features, blood tests and bone marrow biopsy results to classify follicular lymphoma as low or high risk. However, they all define high risk slightly differently. In addition, other factors such as genetic profiling, quantitative measures of the amount of lymphoma in the body, and PET/CT scan results are also important in identifying
people with high risk lymphoma. Similarly, response to treatment can be assessed in a variety of ways, including PET/CT scanning.

The FOLL12 study selected a score known as FLIPI2 to define high risk follicular lymphoma, and PET scanning and ‘minimal residual disease’ (MRD; no evidence of follicular lymphoma in the bone marrow) to assess response to initial treatment. Together, these measures are a strong predictor of outcomes in follicular lymphoma. The FOLL12 study aimed to find out if they can be used to determine whether or not maintenance therapy is necessary for people who respond well to initial therapy for advanced, high risk follicular lymphoma. This approach is known as response-adapted treatment.

**Prepare for your trip and check the forecast**

It’s always wise to research where you’re going so you have an idea of what you might expect when you get there. Of course, however prepared you are, you might meet unexpected surprises along the way.

To this end, the researchers asked: has anyone tried a response-adapted approach to advanced follicular lymphoma treatment before? The PETReA study is testing whether response to initial treatment for follicular lymphoma, assessed by PET/CT scan, can be used to determine who would benefit from maintenance therapy and what maintenance regimen to use. This study is open to recruitment and results are not yet available.

**It is now time to go on your journey!**

The FOLL12 study opened in July 2012. Interim results were presented at the International Conference on Malignant Lymphoma in June 2019. Surprisingly, these results showed that outcomes in the response-adapted arm of the study were not as favourable as outcomes in the standard treatment arm, in which everyone received the same maintenance therapy regardless of their response to initial treatment. This suggests that a complete response to initial treatment, assessed by PET and MRD, is not sufficient to omit maintenance treatment. However, it’s important to note that these are interim results and the full results of the study are not yet available.

**Ask if the journey was worth it**

After any trip, you probably reflect on whether it was worthwhile, if you would go back and what you would do differently if you went again.

In research terms, FOLL12 has certainly provided some valuable results. Unpublished data have confirmed that FLIPI2 and PET scan results after four cycles of treatment are independent predictors of response to treatment in follicular lymphoma. However, there remains a need for better ways of identifying people with high risk disease in order to improve the effectiveness of treatment.

We need better ways to identify people with high risk disease.

In conclusion, treatment of follicular lymphoma should be based on the specific needs of each individual. Most people have low risk disease and it is important that treatments do not do more harm than good.

**De-intensifying treatment regimens in people with low risk follicular lymphoma would be a valuable area for future research.**

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With thanks to Professor Stefano Luminari, Professor of Oncology, University of Modena and Reggio Emilia, Italy for reviewing this article.
As part of the creative writing section of my university degree, I was asked to write about something that had impacted on my life. That wasn’t difficult for me...

Five years ago I was 25, living a family life with a partner and her daughter and I had a full-time job.

I desperately needed a haircut, so headed to my barbers. At the time I had no idea of the impact of something he said to me: ‘You have really thin patches of hair, Dwayne. You might want to get them checked out as it could be alopecia (spot baldness, often on the scalp).’ I decided to see my GP who checked me over and told me it was probably just an allergic reaction to a kitten we had recently taken on.

Over the next 3 or 4 weeks, the patches of hair got worse and it looked like a UFO had come down and made crop circles on the top of my head. My doctor referred me to a specialist at the hospital who took a biopsy from my shoulder and told me to come back in a couple of weeks’ time for the results. My partner came with me when we went back, but I told her she didn’t need to come into the consultation with me. I wouldn’t be long and it would be nothing to worry about. Little did I know!

I was diagnosed with stage 1 mycosis fungoides or MF for short. It was explained to me that it is a type of lymphoma that affects the skin. Because it was early stage and not affecting my health, no treatment was necessary at diagnosis.
I kept going back to the hospital for check-ups and reviews and over time I had about seven or eight biopsies. It came to the point when I was told that they wanted to do five sessions of radiotherapy over 5 days. This was when it really hit me.

They said they would need to make a metal plate for the bottom of my back. I joked: ‘Like Robocop?’ But sadly it was far less cool than that; it was a metal plate in the shape of the top of my bum and back.

I found the five sessions of radiotherapy OK; they involved a fair amount of waiting around, and then me lying down while a large machine zapped me through a hole in the plate that was made for me.

The patches went down and, whether it was coincidence or part of the treatment, my hair grew back, which was massive for me.

Since then, I have only needed to go for regular check-ups.

For quite a while, I was able to put it to the back of my mind, but over time I have realised that emotionally it has affected me far more than I really acknowledge. If I feel unwell at any point – and recently when I had back pain – my first thought is about my lymphoma, and I feel it will always feel present in some way.

Dwayne

DID YOU KNOW?

Cutaneous (skin) lymphoma

Skin lymphomas start in the skin. They are often difficult to diagnose as they can resemble other more common skin conditions. Skin lymphomas differ from other types of low-grade non-Hodgkin lymphoma because treatments are often topical (applied to the skin) rather than systemic (affect the whole body). There are lots of different types of skin lymphoma. Most develop from T cells, with the most common being mycosis fungoides. They are typically chronic (long-term) conditions and are not usually life-threatening.
Understanding blood tests

Blood tests provide important information about how your body is responding to the lymphoma and its treatment.
You are likely to have regular blood tests as part of your diagnosis, throughout your treatment and as part of your follow-up.

**Blood tests are done to:**
- help diagnose a few types of lymphoma (a biopsy is needed to diagnose most lymphomas)
- find out more about the lymphoma before treatment is planned
- check your general health before or during treatment
- assess how your treatment is affecting you
- check whether you have recovered enough from one cycle of treatment before starting the next one
- monitor the lymphoma and your general health during follow-up after treatment and during any periods of active monitoring (or ‘watch and wait’).

Blood tests are done frequently as part of diagnosis and treatment. They are useful in giving your medical team important information about how your body is responding to the lymphoma and its treatment. If you are in follow-up, you are likely to have blood tests at your check-ups but less frequently than you did before. The lymphoma and its treatment can cause frequent changes in your blood results. Your blood test results should be more stable when you are in follow-up, so less frequent tests are needed.

**What do my blood test results mean?**
Your medical team should tell you if your blood test results are normal or if there are any problems. You can ask to see your results, but they can be difficult to interpret. Do not be alarmed if your test results seem to be outside the reference range. Many people have results outside the reference ranges that are not a cause for concern. Your medical team consider your individual circumstances when they look at your blood test results to decide what the results mean for you. Factors they might consider include results from other tests and knowledge of any medical conditions you have. They can explain what your test results mean and don’t be afraid to ask your medical team if anything about your results concerns you.

**What is a ‘reference range’?**
When blood test results come back from the laboratory, they are reported together with a ‘reference range’ (or ‘normal range’). Most people’s results are within the reference range. Around 1 in 20 healthy people have results outside the reference range. Many factors can influence your blood test results, for example, age, sex or ethnicity.

Lab Tests Online have information on reference ranges for common blood tests.
of each type of blood cell is often called the ‘count’.

Blood cells are made from blood stem cells in your bone marrow (the spongy tissue in the centre of your bones). Stem cells are basic cells that can develop into more specialised cells. Blood stem cells can become:

- red blood cells, which carry oxygen around your body
- platelets, which help your blood to clot, preventing bruising and bleeding
- white blood cells, which fight infection as part of your immune system.

Possible low blood counts include:

- **anaemia** – a low count of red blood cells or a low level of haemoglobin in the blood
- **thrombocytopenia** – a low platelet count
- **neutropenia** – a low count of a type of white blood cell called a neutrophil.

Other types of white blood cell might be low too.

You can develop low blood counts for several reasons:

- lymphoma in your bone marrow takes up space needed for healthy blood cells and blood stem cells

Blood tests used for people with lymphoma

There are many different blood tests used for people with lymphoma. The most common is the full blood count.

The full blood count (FBC) is a test that measures how many blood cells there are in your blood. The number in the blood. Haemoglobin is a protein in red blood cells that carries oxygen around the body. Further tests on the blood, such as what the blood cells look like under the microscope, can give other useful information.

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Other types of white blood cell might be low too.

You can develop low blood counts for several reasons:

- lymphoma in your bone marrow takes up space needed for healthy blood cells and blood stem cells
• some treatments stop your bone marrow from working properly as they affect both lymphoma cells and healthy blood stem cells
• some types of lymphoma cause antibodies to form that attack your own healthy blood cells; this is called ‘autoimmunity’.

If you have low blood counts due to the lymphoma, treatment for the lymphoma can help your blood counts recover. Monitoring your blood if you are on ‘watch and wait’ can help your medical team decide when you need to start treatment.

The FBC is a very important blood test when you are on treatment as most treatments for lymphoma can cause low blood counts. These treatments include chemotherapy, antibody therapy and many targeted drugs. Radiotherapy does not usually cause low blood counts unless a large area of your bone marrow is being treated.

If you are having chemotherapy or antibody therapy, your blood counts usually begin to recover a week or two after each treatment. Your medical team monitor your FBC after each treatment to make sure your blood counts are at a safe level for you to have your next planned dose of treatment. If your blood counts are too low, your treatment might be delayed until they recover. Your blood counts usually recover on their own in time but some people are given supportive treatments like growth factors to help boost blood counts.

If you are having a newer drug that you take every day, you have regular blood tests to check how you are responding to the treatment.

**What other blood tests are used?**

Many other blood tests are used for people with lymphoma. For example, they can be done to find out:

• how well your liver and kidneys are working
• whether you have any signs of inflammation – this is done by measuring substances in the blood, such as lactate dehydrogenase (LDH) or C-reactive protein (CRP) and by measuring the erythrocyte sedimentation rate (ESR)
• your plasma viscosity (PV) (the thickness of your blood) – this is an important test if you have Waldenström’s macroglobulinaemia
• levels of abnormal proteins in your blood, measured by serum protein electrophoresis, if you have Waldenström’s macroglobulinaemia
• your blood group (if you need a blood transfusion)
• if you have signs of an infection, which can be measured by the CRP level or from a blood culture (growing any bacteria in your blood)
• if you have or have had a viral infection that could be related to the lymphoma or that could flare up while your immune system is low (viruses such as HIV, hepatitis B virus, hepatitis C virus, cytomegalovirus, or Epstein–Barr virus).

Your medical team might suggest other blood tests depending on your individual circumstances.

**Patient.co.uk** and the **NHS website** have more information on blood tests. **Lab Tests Online** has an index with more detailed information on many different blood tests.

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PERSONAL EXPERIENCE

I have been in remission from Burkitt lymphoma, a type of high-grade non-Hodgkin lymphoma, for over 12 years.

What had started as backache and a lump in my armpit, saw me referred to my local hospital.

I had a series of meetings with consultants and many tests later was told I had lymphoma, but that further tests were needed to identify the exact type.

On 4 November 2006, I was diagnosed with Burkitt lymphoma, stage 4.

Venturing into the unknown was frightening, especially when I was told I had a rare cancer that my medical team had not treated before. As for me, I had barely heard of the word ‘lymphoma’. Looking back, I walked into hospital relatively fit but left, several months later, bald, feeling lousy and incapable of walking unaided.

I had been told my lymphoma was aggressive and would be treated aggressively with full-time stays in hospital, where I would be given R-CHOP chemotherapy and methotrexate. Unfortunately I had a reaction to the latter, endured C. difficile and developed sepsis, which was life-threatening and reduced my mobility significantly.

I had tubes, cannulas, Hickman® and PICC
The real highlight was on 23 April 2007. I had braced myself for the worst, so it was actually a shock when I was told I was in remission. I still celebrate this date.

While my treatment had finished, my recovery had only just begun. The question I had to face was how to move on from feeling ‘institutionalised’ to returning to the ‘real world’ and adapting to a ‘new normality’.

To help with this, I received support from specialist nurses and had regular check-ups with my consultant over 5 years.

I became a member of a Lymphoma Action Support Group and am a Buddy. I am also a member of the Reader Panel that ensures the organisation’s information is easily understood. This has kept a link which has helped me stay informed of latest developments in treatments for lymphoma. At a local level, I have been a cancer buddy for over a decade at the hospital that saved my life.

Cancer changed me in a variety of ways: hair loss, scarring, weakened muscles and lack of feeling in toes and fingers. I had got into habits that still continue, like wetting my head under the shower as I did when I had no hair. These are minor concerns in comparison with the emotional and mental problems I have faced. There is the frustration of not being able to do things I could do before. Some of this I have put down to ‘chemo brain’, which causes me problems with concentration and with finding the correct word. Surprisingly though, I have become more creative and
enjoy many crafts that I would not have tackled in the past.

Because my immune system was compromised when I was being treated, I have become paranoid about infection control; I hesitate to shake hands with people and nothing is designed to infuriate me more than someone sneezing close by, even after all these years.

If I have aches, pains or unexplained lumps, I do not hesitate to see my doctor. No, I am not turning into a hypochondriac, but I am only too well aware that cancer generally needs to be identified quickly and I do not propose to take any chances.

Travel was important to me before cancer so I was delighted to discover there were a number of companies who would provide travel insurance, albeit after some detailed questioning about my pre-existing medical condition and at an increased price.

One important message I have is the need to care for carers. Family and friends have to master their own fears. Cancer impacts upon whole families, friends and communities. Relationships can change. Those that matter continue as before; others may change beyond recognition.

Having undergone treatment for cancer, I have changed as a person and, I am told, am more sensitive to others experiencing difficulties. It has also reaffirmed my belief in the importance of gratitude and living life to the full.

Kathleen

**DID YOU KNOW?**

**More about Burkitt lymphoma**

Burkitt lymphoma is a very fast growing type of high-grade non-Hodgkin lymphoma.

- It develops from B lymphocytes (white blood cells that fight infection).
- Symptoms often develop quickly, over just a few days or weeks.
- Treatment usually begins very soon after diagnosis with a combination of strong chemotherapy drugs and antibody treatment rituximab.
- Most people stay in hospital for most or all of their treatment, which can take several months.

- It is uncommon – about 250 people are diagnosed with Burkitt lymphoma every year in the UK.
- It is the most common type of non-Hodgkin lymphoma in children, although it can occur at any age.
- It affects about three times more men than women.
The National Cancer Research Institute (NCRI) held its 49th Annual Lymphoma Trials Meeting in London in November. Researchers and healthcare professionals from across the UK came together to share the latest news on lymphoma clinical trials.

**High-grade non-Hodgkin lymphoma**

Dr Chris Fox, Consultant Haematologist at Nottingham University Hospitals NHS Trust and chair of the NCRI high-grade lymphoma clinical study subgroup, gave an overview of the group’s recent achievements.

The group currently has 16 academic-led studies open for recruitment across the UK, with a further nine due to open soon. These cover a variety of lymphomas, including diffuse large B-cell lymphoma (DLBCL), primary or secondary central nervous system (CNS) lymphoma, Burkitt lymphoma, primary mediastinal large B-cell lymphoma (PMBL), post-transplant lymphoproliferative disorder (PTLD) and peripheral T-cell lymphoma.

In the past year, four clinical trials have completed recruitment:

- **INCA**, a study looking at whether an antibody–drug conjugate called inotuzumab ozogamicin, in combination with chemo-immunotherapy, is effective for people with DLBCL who can’t have standard treatment.
- **IELSG 37**, a study to find out if radiotherapy to the chest can be safely omitted in people with PMBL who have had a good response to chemo-immunotherapy, as determined by an end of treatment PET/CT scan.
- **TIER**, an early phase study testing a chemo-immunotherapy regimen called TIER in people with primary CNS lymphoma that has come back (relapsed) or not responded (refractory) after initial treatment.
- **ROMICAR**, an early trial testing targeted drugs called romidepsin and carfilzomib in people with relapsed or refractory peripheral T-cell lymphoma.

Look out for updates on Lymphoma TrialsLink on our website as these trials progress and results become available.
Clinical studies that are planned for the future include trials looking at:

- whether adding the targeted drug acalabrutinib to R-CHOP chemo-immunotherapy is beneficial for people with DLBCL
- whether polatuzumab vedotin plus chemo-immunotherapy is a suitable option for people with DLBCL who have other illnesses that mean they can’t be treated with full dose CHOP
- whether adding polatuzumab to R-ICE chemo-immunotherapy improves outcomes in people with relapsed or refractory DLBCL
- whether DA-EPOCH-R produces better outcomes than R-CODOX-M/R-IVAC in people with Burkitt lymphoma
- whether an oral form of the chemotherapy drug azacitidine is effective in certain types of relapsed or refractory T-cell lymphoma.

Low-grade non-Hodgkin lymphoma

Dr Kim Linton, Consultant Medical Oncologist at the Christie Hospital, Manchester, and chair of the low-grade non-Hodgkin lymphoma clinical study subgroup, presented information on current and planned trials in low-grade lymphomas.

The group has many open trials covering front-line and subsequent treatment for a variety of different low-grade lymphomas. Large ongoing trials include:

- PETReA, which is studying whether PET scans can be used to develop risk-adapted maintenance therapy for follicular lymphoma after initial treatment ends
- MCL Biobank, an observational study that hopes to find markers to identify whether people have slow-growing or fast-growing mantle cell lymphoma when they are diagnosed
- ENRICH, which is comparing rituximab plus ibrutinib with chemo-immunotherapy in people over 60 with mantle cell lymphoma who are not able to have a stem cell transplant
- PembroWM, a trial testing whether a combination of rituximab and pembrolizumab is safe and effective for people with relapsed or refractory Waldenström’s macroglobulinaemia.

Interesting trials in set-up or early development include:

- the RAINBOW trial, which will compare rituximab plus ibrutinib with standard dexamethasone, cyclophosphamide and rituximab (DCR) as initial treatment for people with Waldenström’s macroglobulinaemia
- REFRACT, which aims to compare new, targeted treatments with standard chemo-immunotherapy in people with relapsed or refractory follicular lymphoma
- IELSG 48, which intends to compare rituximab with or without acalabrutinib in people with splenic marginal zone lymphoma
- REFLECT, an observational study that aims to find biomarkers to help identify people with relapsed or refractory follicular lymphoma who might benefit from having an autologous stem cell transplant.
Overall, the lymphoma clinical studies group has achieved considerable success over the past year and continues to work towards better outcomes for people with all types of lymphoma.

Hodgkin lymphoma

Dr Graham Collins, Consultant Haematologist at Oxford University Hospital and chair of the Hodgkin lymphoma clinical study subgroup, explained why continuing research into Hodgkin lymphoma is so important.

Although outcomes in Hodgkin lymphoma are typically excellent, there is always room for improvement. Ongoing and future research aims to optimise cure rates while minimising the occurrence of side effects and late effects. In particular, researchers are keen to develop better prognostic tools – measures to help predict who will respond well to particular chemotherapy regimens, and which can be used to guide individual chemotherapy choices. Research also aims to identify effective, less toxic chemotherapy regimens suitable for older people or those with other medical conditions who are not able to tolerate standard chemotherapy.

Cutting-edge research is also hoping to use biomarkers (molecular or genetic tests) to identify people with relapsed Hodgkin lymphoma who are at low risk of further relapse. This could help differentiate between people who need an autologous stem cell transplant and people who will do just as well without one.

Researchers at the University of Oxford are developing an online decision support tool for Hodgkin lymphoma. The researchers intend to analyse data comparing the survival benefits of radiotherapy in early-stage, favourable Hodgkin lymphoma against the risk of developing late effects in the future. They plan to use this data to develop a decision tool that weighs up these benefits and risks on an individual basis. This will help people make informed decisions about their own treatment.

One study due to open soon aims to find out whether replacing the bleomycin component of ABVD with brentuximab vedotin is beneficial in people with early-stage Hodgkin lymphoma, and whether a PET scan after two cycles of treatment can help determine whether or not radiotherapy is required.

A final planned trial is hoping to confirm whether or not a special way of analysing PET scans at diagnosis can be used in people under 60 with advanced Hodgkin lymphoma to work out who needs intensive chemotherapy and who can be treated effectively with less intensive regimens. This trial is also looking at incorporating new, targeted treatments into regimens commonly used to treat advanced Hodgkin lymphoma.

Acknowledgements:

With thanks to the following for reviewing this update:

Dr Chris Fox, Consultant Haematologist at Nottingham University Hospitals NHS Trust and chair of the NCRI high-grade lymphoma clinical study subgroup.

Dr Kim Linton, Consultant Medical Oncologist at the Christie Hospital, Manchester, and chair of the low-grade non-Hodgkin lymphoma clinical study subgroup.

Dr Graham Collins, Consultant Haematologist at Oxford University Hospital and chair of the Hodgkin lymphoma clinical study subgroup.
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Find out more at lymphoma-action.org.uk/Kenya
Ideas, inspiration and guest speakers

Kevin explains how attending a Lymphoma Action Support Group helped him cope.

In August 2016, and at the age of 58, I attended a routine male annual MOT check-up at the doctors.

The blood tests came back normal, but I mentioned that I was having night sweats. Three days later, but still feeling fit as a fiddle, I was in a CT scanner, joking with the nurses.

The scan revealed that something was looking worrying on my lung, and further tests were needed. I recall going swimming the next day, and instead of my usual 32 lengths, all I could manage was four. Something was clearly not right.

I had a biopsy taken from the lymph node in my neck. The 2 week wait for the biopsy results was a really worrying time.

I was diagnosed with stage 4 B-cell non-Hodgkin lymphoma, 80% high grade and 20% low grade. My wife burst into tears and my first thought was that I would never see Liverpool FC win another trophy.

From that diagnosis I went downhill pretty quickly. I started chemotherapy in October 2016 with six sessions of R-CHOP, 21 days apart. My hair fell out after one session, but worse was to come. The lymphoma affected my spine and my bones were breaking. After five chemotherapy sessions I went downhill fast. I could hardly walk unaided and ended...
up on walking sticks, then a wheelchair. I couldn’t move an inch without being in agonising pain so, against my wishes, I was talked into going into a hospice. They do fantastic work to relieve pain and the staff were fantastic too.

After my final chemotherapy, I had a scan which showed that I was not clear of the lymphoma, so a further two intense chemotherapy sessions were planned. I was scared stiff, but my wonderful wife sat with me through every minute, as she had with the previous six sessions.

The next few months were a blur; scans, blood tests, hospital appointments and also my first Lymphoma Action Support Group. The meeting was terrific. There were around 20 other people with similar problems and loads of ideas, inspiration, plenty of guest speakers and stories to note. They are held every 8 weeks and I don’t think I have missed one. My wife Ki comes with me – she doesn’t like to miss out!

In May 2017 I got the news I had been waiting for. I was clear of the lymphoma for now, and was officially in remission. The chemotherapy was followed by maintenance rituximab injections for 2 years every 8 weeks.

I returned to work as a finance officer in October 2017. I have been back 2 years now and not had a day off sick. I work for a charity and they have been brilliant and kitted me out with a desk riser and a special chair so I can stand and work.

I have been told by my GP that I will never climb mountains, but I am more than happy and take every day as it comes.

I am now on active monitoring, or watch and wait, like thousands of other people with lymphoma and love it when I see stories of people still on it 10 or 20 years later.

I still attend the Lymphoma Action Support Group and hope that I can help others who are facing the same problems as me.

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
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