lymphoma matters

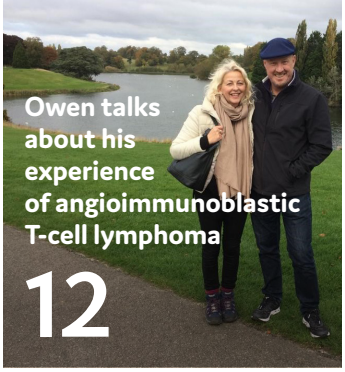
ISSUE 116 | SPRING 2020

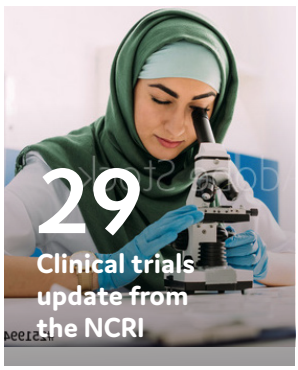
Your blood tests

Insight into pathology

Clinical trials update

Lymphoma action





Contents

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among people aged 15 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.

Editor: Anne Hook
Cover: Georgia, who features in our revised *Young person's guide to lymphoma* (see page 6)

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

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Lymphoma action

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(BMA) awards in the 2019 BMA Patient Information Awards (see more on page 4) and were voted 'Most Dedicated UK Cancer Charity 2019' in the Global Healthcare and Pharmaceutical Awards.

Finally, on Sunday 3 November at 7.54am and 9.25pm, listen out for Carol who will be sharing her experience of lymphoma on the BBC Radio 4 Appeal. You can also catch up on Thursday 7 November at 3.27pm.

Read more about our work online in *Our impact in 2018* at lymphoma-action.org.uk/Impact2018

Can you please strip in the FSC logo here as per old editions

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 the illness.

Worryingly, Macmillan's 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.

Positive news from the NHS

It was good to see the recent news stories from the NHS, like the proposal to cut car-parking charges for cancer patients.

The NHS also reported on their intention to focus on pre-habilitation, where people are given more help in preparing physically before treatment or surgery, in order to improve recovery time after treatment.

It was also interesting to read about the first social prescribing organisation, which is due to start in January 2020. Social prescribing is a way for people to be put in contact with link workers; people who give time to individuals to focus on what really matters to them and put them in touch with people or organisations who can help them with their health and wellbeing.

Look out for updates on the news section of our website lymphoma-action.org.uk/News

Lymphoma Action volunteers named Best Volunteer Fundraisers of the Year!

We are delighted for Marguerite Russell and David Cooke on their well-deserved win at the Institute of Fundraising East Anglia Regional Awards in November 2019.

Their efforts, as part of the Norfolk Lymphoma Action Fundraising Group, have raised over £183,000 for us since the group was set up in 2003.

David and Marguerite both have experiences with lymphoma that drive them to work tirelessly to help others affected by the condition. David received a diagnosis of non-Hodgkin lymphoma in 2001, and Marguerite's sister passed away from lymphoma in 2009.

'We cannot thank Marguerite, David and the rest of the Norfolk Lymphoma Action Fundraising Group enough for their hard work and dedication', said Carly Benton, Lymphoma Action Volunteering Development Manager. 'We are so pleased that they have been given the recognition they thoroughly deserve.'

Marguerite receiving her award

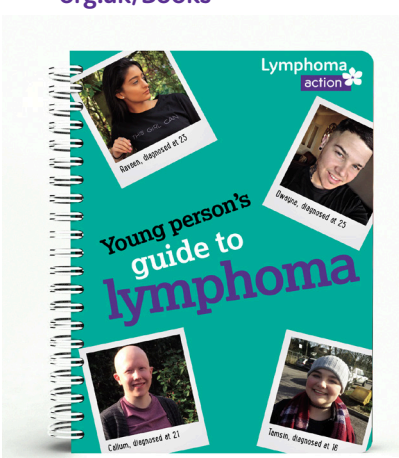
New information now available

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

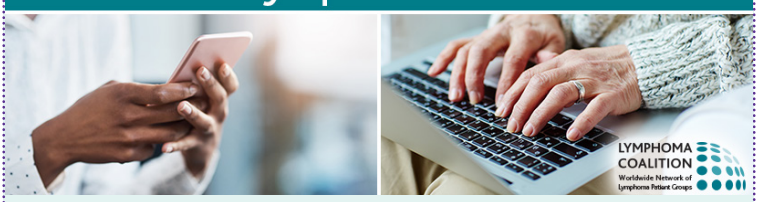
We have recently revised three of our books:

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

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



2020 Global Patient Survey on Lymphomas & CLL



Share your experiences in the Lymphoma Coalition 2020 Global Patient Survey – hurry, the survey closes on 11 March 2020!

Every two years, the *Lymphoma Coalition* – a non-profit network of patient organisations across the world of which we are a member – conducts a global survey of patients with lymphoma and CLL and their family, friends and caregivers.

The 2020 survey is your opportunity to share what your lymphoma experience has been like. Whether the diagnosis was recent or many years ago, we want to hear from you!

The survey data will be used locally and globally to:

- improve support services
- advocate for change
- provide relevant facts and statistics.

Please complete the survey online by 11 March 2020 at lymphoma-action.org.uk/Global

Join our fabulous

FAMILY EVENT

Bridges of London Walk

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. You have the whole day to complete the 9 km walk.

Walking from Vauxhall Park to Tower Bridge by criss-crossing over 11 bridges is one of the best ways to see the capital, with plenty of time to take in all the sights and 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 4-16 £5, Children under 3 free.

We ask that you 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 and 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

Insight into pathology

Consultant Haematopathologist Bridget Wilkins answers your questions on pathology

ask the expert

Does the diagnosis of lymphoma always rely on a biopsy?

It is 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. Chronic lymphocytic leukaemia is a classical example of a lymphoma that shows up in the blood. When the same disease (we don't know yet why it does) stays put in lymph nodes, 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 circulation 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 recurs after treatment, a biopsy is often not needed for confirmation, as imaging studies (MRI, PET and CT scans, for example)

can be sufficient. 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, 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

In general, pathologists 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, 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, your medical team of doctors, nurses, scientists and therapists 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.

We need to make sure that all the different pieces of the jigsaw puzzle fit.

Why does it take about two 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 and 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 lab. This is expensive so they are batched to keep the cost 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, at present, 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 of the slides and 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, overseas etc)?

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 pathologists happen 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 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 week; 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.

Every lymphoma diagnosis is discussed at the MDT meeting by a member of the pathology team.

I REALLY DIDN'T WANT THIS TO BE LYMPHOMA

Owen talks about his diagnosis of angioimmunoblastic T-cell lymphoma and his family history of lymphoma

"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 2 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 1 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.

Yvonne and I were devastated by the diagnosis, but 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 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.

We were devastated by the diagnosis.

My family were amazingly resilient, and this helped.

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.

Did you know?

Angioimmunoblastic T-cell lymphoma is often fast-growing and affects more men than women. Most people are diagnosed at an advanced stage and are treated with chemotherapy. If fit enough, people may be recommended a stem cell transplant.

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.

I was in no doubt the transplant was the right course of action.

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 three 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.

We hoped a short family break would be a chance to relax, but all it did was spread the anxiety.

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.

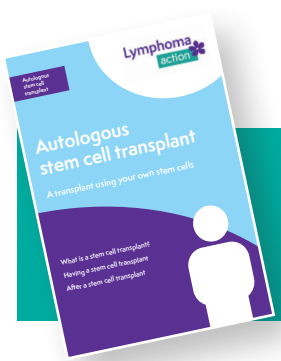
By early May I realised I was struggling. I felt very tired, still had some digestive problems, and also could not achieve the closure to my lymphoma experience I wanted. I spoke to a psychological nurse who helped me to think about my life after lymphoma. I needed to adjust my work life balance.

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 (genetic differences between different people) 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.



We have recently revised our book, *Autologous stem cell transplant*. Download or order a copy at lymphoma-action.org.uk/ASCT

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 3-7 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.**

APRIL
Easter fun

We are egg-static and leaping with joy that it's Easter! We are looking for schools, businesses and community groups to join our two egg-citing Easter activities. We want to get the country hunting in aid of Lymphoma Action by holding **egg hunts**. They can be virtual, around the office or even in your own back garden. Children will enjoy our **LEAP for lymphoma** where we are encouraging them to be sponsored to bunny leap for lymphoma. Contact the fundraising team for a pack, including bunny ears!

We have an Easter pack available to download with masses of great Easter fun ideas for adults and children at **www.lymphoma-action.org.uk/Easter**

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. **www.lymphoma-action.org.uk/Lunch**

Any particular food?

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. **Please let us know if you would like a fundraising pack.**

IT'S SPRING

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) produces two potent alkaloids – vinblastine and vincristine – which are used to treat various cancers, including Hodgkin lymphoma. Once your seeds have grown we would love to see your photos, so please share them on social media at #Lymphoma Matters.

Don't forget periwinkle seeds and pin badges are perfect for wedding favours and are available in our shop.

PURPLE PLATES

If you have a favourite restaurant then please don't forget to mention Purple Plates. Participating restaurants automatically add £1 to customer's bills, to be donated to Lymphoma Action. This can be removed at the diner's request. The eateries also display information posters and small Lymphoma Action place cards in their establishment, so it's a great way to raise awareness of signs and symptoms. We will add the restaurant details on our website, so it's great advertising for them.

PURPLE PLATES

For further information please ring Sarah on 01296 619419 or email fundraising@lymphoma-action.org.uk

You make us amazonsmile

We wanted to thank everyone supporting us when they shop with AmazonSmile.

Last year our brilliant supporters raised hundreds of pounds while they shopped, to help us make sure no one has to face lymphoma alone.

AmazonSmile is a website operated by Amazon. It has the same products and prices but has one big difference; 0.5% of the purchase price of eligible products is donated by the AmazonSmile Foundation to the charity of your choice. If you would like to support us while you shop, simply go to smile.amazon.co.uk and select Lymphoma Action. Alternatively, if you are using the Amazon app, go to the settings menu and select **AmazonSmile** to turn on donations.

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 longer 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.

We need to identify people with high-risk disease.

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.

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.

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

PERSONAL EXPERIENCE

MY CANCER WITH THE STUPID NAME

Dwayne talks about his diagnosis of mycosis fungoides

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 week's 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 had no idea of the impact that trip to the barbers would have.

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 7 or 8 biopsies. It came to the point when I was told that they wanted to do 5 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.

They needed to make a metal plate to protect me during radiotherapy. I pictured 'Robocop' but in reality it was far less cool.

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

If I ever feel unwell, my first thought is my lymphoma.

DID YOU KNOW?

About cutaneous (skin) lymphoma

Skin lymphomas start in the skin. They are often difficult to diagnose as they 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-threating.

Understanding blood tests

Blood tests provide important information about how your body is responding to the lymphoma and its treatment.

We have received a number of enquiries asking for more information about blood tests; why they are done and what the results tell us. In this short article, we hope to answer some of these questions.

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

Don't be afraid to ask your medical team if anything about your results concerns you.

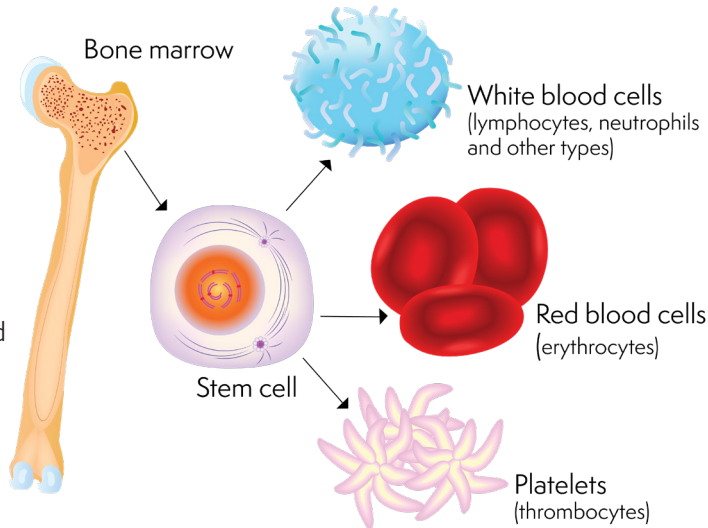


Figure: The different blood cells that develop from stem cells
New blood cells are released from the bone marrow into the bloodstream.

tests. However, blood tests are not done in the same way in all laboratories. Laboratories might have slightly different ranges, use different techniques or might use different units to report their results. Your medical team are best placed to advise about your blood test results as they know your individual circumstances.

You can ask to see your blood tests, but they can be difficult to interpret.

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 of each type of blood cells 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:

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

Why is the full blood count done?

A FBC checks for low blood counts. It also measures how much haemoglobin there is 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.

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

- 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 healthly 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 inflamation - 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
- serum protein electrophoresis to measure abnormal proteins in your blood - 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 **NHS Choices** have more information on blood tests. **Lab Tests Online** has an index with more detailed information on many different blood tests.

Acknowledgements: With thanks to Dr Bhupinder Sharma, Radiology Consultant, The Royal Marsden Hospital NHS Foundation Trust, London, for reviewing this article. This is an edit of detailed information which can be found at lymphoma-action.org.uk/BloodTests

‘The past is a foreign country: they do things differently there.’

LP HARTLEY

I’m not the same person I was before my diagnosis of Burkitt lymphoma – KATHLEEN

‘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-difficil and developed sepsis, which was life-threatening and reduced my mobility significantly.

I had tubes, cannulas, Hickman® and PICC

lines for chemotherapy. There were tubes to feed me and catheters to remove urine. I was unable to get in or out of bed. I could not clean, wash and dress myself, or feel my feet. I needed help for the most basic of tasks. I could no longer read, concentrate or sleep. Worst of all was the inability to enjoy food and the continuous nausea.

The most overwhelming feeling throughout the process was fatigue. Clinical staff warned me about this, but in all honesty, I don't think they understand how debilitating this can be. I remember my sister and her son visiting me in hospital and not having the strength to reach out and put on my glasses. Without being able to see them, I was unable to communicate with them effectively, and that memory still haunts me.

Despite enduring the treatment, there were a number of things that have stayed with me:

- the incredible support offered by my late husband, family and friends
- the wonderful care and consideration I received from my medical team
- the honesty of my consultant
- living on banana milk-shakes, ice-pops and the picnics provided by my late husband
- the joy of having a shower for the first time in many days
- certain TV programmes that still remind me of my time in hospital. I can't watch 'Strictly Come Dancing' without thinking about chemotherapy.

The most overwhelming feeling throughout the process was fatigue.

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.

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.

Cancer impacts upon whole families, friends and communities.

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 is uncommon – about 210 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.
- 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 chemo drugs and antibody treatment rituximab.
- Most people stay in hospital for most or all of their treatment, which can take several months.

49TH ANNUAL LYMPHOMA TRIALS MEETING

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 immunochemotherapy, 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 immunochemotherapy, as determined by an end of treatment PET/CT scan
- **TIER**, an early phase study testing an immunochemotherapy 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 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 immunochemotherapy is beneficial for people with DLBCL
- whether polatzumab vedotin plus chemoimmunotherapy 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 chemoimmunotherapy 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 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 chemoimmunotherapy 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.

Visit Lymphoma TrialsLink for more information about these trials, including details of who might be eligible to take part.

Interesting trials in set-up or early development include:

- The **RAINBOW** trial, which will compare rituximab plus ibrutinib with standard dexamethasone, rituximab and cyclophosphamide (DCR) as initial treatment for people with Waldenström's macroglobulinaemia
- **REFRACT**, which aims to compare new, targeted treatments with standard chemoimmunotherapy 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 identify 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.

Fundraising trek pages - I will add in once approved

Fundraising trek pages - I will add in once approved

Lymphoma Action Support Groups

Aylesbury
Bangor
Bath
Bolton
Brighouse
Cambridge
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Cardiff
Cheltenham
Chester le Street
Colne
Darlington
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Glasgow
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Mold
Nantwich
Norwich
Peterborough
Plymouth
Poole
Portsmouth
Preston
Reading
Southampton
Southport & Ormskirk
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Truro
NEW Walton
Warwickshire
Wigan
Wirral

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**.

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 4. 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 6 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 5 chemotherapy sessions I went downhill fast. I could hardly walk unaided and ended up

At the group you meet people with similar problems, share loads of ideas and get to hear from guest speakers.

Kevin (second from left) with his wife and family.

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 2 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 meeting. 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 run 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 Barnardos 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.

"The Lymphoma Action Support Group meetings are fantastic.

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

Lymphoma action

Lymphoma Focus Day

Saturday 16 May 2020

etc.venues Manchester, 11 Portland Street, Manchester M1 3HU

Join our Lymphoma Focus Day (national conference)

Whether you're newly diagnosed, on active monitoring, having treatment, finished treatment or are a family member, friend or carer – this is the event for you.

Hear from expert speakers and meet others who 'get it' in a warm and friendly environment.

Topics

Types of lymphoma
Looking after yourself
Emotional and practical toolkits
Diet and nutrition
New and future treatments

Tickets £30. Find out more and book your place.

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