

lymphoma matters

ISSUE 120 | SUMMER 2021

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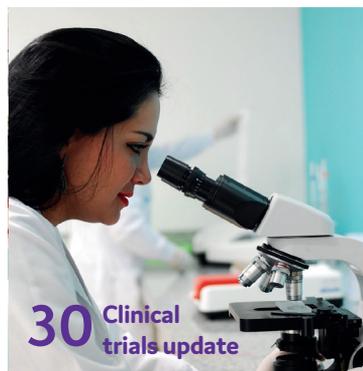
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for 35 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment, and aftercare of lymphoma. We're here for you.

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

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Editor: Anne Hook
Cover: Actor Jamie Beamish, who you might recognise from *Bridgerton* and *Derry Girls* shares his Hodgkin lymphoma experience (see page 14).

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

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Ropinder Gill
Chief Executive

We are closely following studies on vaccine efficacy. Find out more on page 5.



We hope you like this edition of *Lymphoma Matters*. You can sign up to regularly receive our magazine at lymphoma-action.org.uk/Sign-Up

Supporting you for 35 years

Welcome to your summer edition of *Lymphoma Matters* which is packed full of useful information and resources. I hope it also gives you an idea of the breadth of our work thanks to your support and generosity.

We are still here for you if you have concerns about the impact of COVID-19, or queries around vaccines. We have included an article in this issue that addresses COVID-19 vaccination concerns for people affected by lymphoma, and will continue to update our website as and when new information emerges. In the meantime, we are continuing to support vaccine efficacy studies and push for more information and data on what this means for people living with lymphoma.

All the while we continue to build on the digital support and services we put in place over the last year and a half – many of which you can read about in our 2020 Annual Accounts and Report, and our Impact Report, which is available on our website.

Whilst we understand that 2021 is a challenging second year of COVID-19, it is still a special year for us as we mark our 35 year anniversary. It is amazing to see how far we have come since 1986 and to reflect on the impact we have made. It is safe to say that none of what we have achieved would have been possible without your support and involvement.

We hope that you will help us mark our 35 year anniversary by supporting us in whatever way you see fit. This could be as simple as liking one of our social media posts, as special as remembering us in your will, as social as taking part in our anniversary tea fundraiser, or as unique as taking up one of our virtual London Marathon places. Whatever you choose to do, we remain so grateful to all our supporters and we hope that you stay safe, stay well and most of all, remember that we are here for you however you need us.

Ropinder Gill
Chief Executive

Lymphoma Action welcomes new trustee

We are delighted to welcome Shaf Mansour as a trustee of Lymphoma Action. Shaf recently joined our Board of Trustees, and brings over 10 years of experience in the charity sector.

Shaf commented: 'I'm honoured to be joining Lymphoma Action at this incredibly exciting time as the charity grows from strength to strength.'

Our Chair of the Board of Trustees, Gordon Johns, commented: 'We have been keen to seek a trustee with digital and ICT strategy experience to support the organisation and help us increase our reach even further. Shaf brings with him a wealth of experience within this area and we are looking forward to working with him.'



Can you help shape future lymphoma research?

The University of Manchester/Christie Hospital NHS Foundation Trust Lymphoma Research PPIE Group (EMERGE) are looking for 'e'. If you are a patient or carer of someone with lymphoma, you could help to prioritise research, offer advice as a member of a project steering group, comment on research materials and participate in interviews with research participants.



If you are interested, please contact Dr Tania Seale at tania.seale@manchester.ac.uk

Have you been treated for Hodgkin lymphoma?

Researchers at The University of Manchester are looking for people aged 18 or over, who have been treated for Hodgkin lymphoma. They need participants to review an information booklet about lung cancer screening after Hodgkin lymphoma. Taking part involves an online survey and/or an online focus group.

For more details visit engagehl.com or email rachel.broadbent-2@postgrad.manchester.ac.uk

Skin lymphoma news

Lymphoma Action are proud to be the patient voice in health technology assessments. In skin lymphoma, we were among the organisations who successfully appealed against the decision not to approve mogamulizumab in England, Wales and Northern Ireland. NICE will now review the decision.

Addressing COVID-19 vaccination concerns for people with lymphoma



We know that people with lymphoma are at higher risk than other people of becoming seriously ill if they develop COVID-19. This is why they were prioritised for vaccination when it first became available in the UK. However, we also know that people with lymphoma often have lowered immunity and might not respond to vaccines as well as other people.

Although the coronavirus vaccines have all been tested in very large clinical trials involving tens of thousands of people, the trials didn't include people with lymphoma. This means, at the moment, that there is limited information on how well the vaccines work in people with lymphoma.

In April, we reported on the results of a trial that suggested people with lymphoma have a lower antibody response to coronavirus vaccination than the public at large. This trial included 32 people with lymphoma or CLL. Early results suggested that many people with lymphoma might not make sufficient protective antibodies in response to the coronavirus vaccine, but the small number of people with lymphoma who took part makes it difficult to draw any firm conclusions.

Most of these people only had one dose of the vaccine, and we don't know how a second dose affects the antibody response in people with lymphoma. It's important to remember that the immune system is very complicated. Antibodies aren't the only way your body responds to vaccination (although they are the easiest response to measure). We don't know yet how other parts of your immune system respond to the vaccines, or how antibody levels relate to your overall protection from COVID-19.

Another study has measured antibody responses in people who had their vaccine as part of the UK vaccination programme, rather than a clinical trial. This study included over 8,500 people. Of these, 74 reported that they had blood cancer. The data released so far does not specify what types of blood cancer, so we don't know how many people had lymphoma. Early results found that 70% of people with blood cancer produced antibodies within 28 days of having their first vaccination. Although this is lower than in people without blood cancer, it is more encouraging than some other studies report. After a second dose of vaccine, the proportion of people with blood cancer who had an antibody response increased to 80%.

People with blood cancer had significantly lower antibody levels than people without blood cancer, but we don't know what this means in terms of the level of protection against COVID-19. Low antibody levels may still offer useful protection, while normal antibody levels do not guarantee complete protection against COVID-19. It is important to note that the number of people with blood cancer in this trial was small, and that the results haven't yet been published or reviewed by other scientists.

Even if you don't respond fully to vaccination, the health professionals we have spoken to have stressed that **'Any protection is better than none.'** This is why we recommend the flu vaccination every year, even when people are receiving chemotherapy. However, we know how anxious you might be about the risk of COVID-19, especially if you feel that you have little protection even with the vaccine.

Lymphoma Action is working with other blood cancer charities and with a broader group of charities to keep vaccine efficacy at the top of the agenda and put the concerns of all of our beneficiaries to the Joint Committee on Vaccination and Immunisation (JCVI).

These aim to find out more about how well the vaccines work in people with lymphoma and other blood cancers. These include the PROSECO trial, which is looking specifically at how effective coronavirus vaccination is in people with lymphoma. We endeavour to support these trials by raising awareness of the trial sites (currently Leicester, Norwich, Nottingham, Newcastle, Oxford, Portsmouth and Southampton). The PROVENT trial is looking at whether lab-made antibodies can help prevent COVID-19 in people who can't have (or don't respond to) vaccination.

It is encouraging that this research is taking place, but it will be a while before results are available. We will report results as soon as we have access to them.

In the meantime, irrespective of your health status or predicted antibody levels, it is important to follow the government guidance and continue to take extra precautions to reduce your risk of infection. We have more information in our guidance for clinically extremely vulnerable people on our website.

With thanks to Consultant Clinical Oncologist Dr Eve Gallop-Evans for reviewing this update. Information correct as at 10 June 2021. Updates are posted on our website regularly.

Prize Draw



Take part in the Lymphoma Action Prize Draw, and help us give much needed support to people living with a lymphoma diagnosis.

Be in with a chance to win £1,350 or one of our other fabulous cash prizes! Every ticket bought helps us to continue our work ensuring that no one faces lymphoma alone. Please visit lymphoma-action.org.uk/PrizeDraw to find out more, call the Fundraising Team on 01296 619419 or email fundraising@lymphoma-action.org.uk

The draw will take place on Wednesday 1 September 2021.

Keeping safe in the sun

Some treatments for lymphoma can make your skin more sensitive to sunlight (photosensitive). This includes radiotherapy, many chemotherapy drugs and some supportive drugs.

Although summer is the time you are most at risk, it is important to keep safe in the sun throughout the year. Even on cloudy days, it is important to protect yourself from the effects of ultraviolet (UV) rays.

What are ultraviolet (UV) rays?

Sunlight consists of UVA and UVB rays. UVA rays stay at equal levels throughout the year; whereas UVB rays are at their most intense during the summer, around midday and at high altitude. It's UVB rays that causes sunburn.

How can I protect myself from the effects of the sun?

The following tips are aimed to help you stay safe in the sun, and are especially important to follow after treatment for lymphoma.

- Avoid being in the sun when the rays are at their strongest, between 11am and 3pm.

- Keep radiotherapy sites covered in the sun. Many chemotherapy drugs and some supportive drugs (especially some antibiotics and diuretics) can make the skin more sensitive to sunburn from UV rays.
- Use a sunscreen with a 'sun protection factor' (SPF) of 30 or higher and choose one that protects against both UVB and UVA rays. The SPF is the level of protection against UVB, while the stars on the bottle (1 to 5) show the level of protection against UVA.
- Use clothing to help protect yourself from the effects of sun such as a wide-brimmed hat (caps don't protect your neck or ears), and long sleeved shirts and trousers.
- Wear sunglasses that have a guaranteed UV light filter.

With thanks to Lisa Castallaro, Haematology CNS, for reviewing this information.

Active monitoring or 'watch and wait'



Picture: Russ, on active monitoring, and his partner

With thanks to Dr Chris Fox, Consultant Haematologist, Nottingham University Hospitals NHS Trust and the panel of experts who addressed these questions at a Lymphoma Action and Leukaemia Care joint webinar held in April 2021.

What is active monitoring?

Sometimes, lymphoma doesn't need treatment straight away. Instead, people have regular check-ups with their medical team to monitor their health and to see how the lymphoma is affecting them. Treatment doesn't start straight away unless the lymphoma begins to cause significant health problems.

Active monitoring or 'watch and wait' is a recognised form of management for some lymphomas, as well as other cancers, such as prostate cancer.

When might active monitoring be used?

Active monitoring is commonly used for low-grade non-Hodgkin lymphomas like follicular lymphoma, chronic

lymphocytic leukaemia (CLL), marginal zone lymphoma and some types of mantle cell lymphoma. These low-grade non-Hodgkin lymphomas can be difficult to cure completely, but can often be controlled for many years, only needing treatment from time-to-time.

If you are newly diagnosed with a low-grade lymphoma that isn't causing troublesome symptoms, active monitoring might be suggested. Your medical team will assess the risk of the disease progressing. If they conclude that the risk is low, they are likely to recommend active monitoring.

I had geared myself up for treatment and it going away, but that is not the case. It is about finding a new way to live my life and learning not to be fearful of the lymphoma.

Abi, on active monitoring for follicular lymphoma

Your medical team might also suggest active monitoring to give them more time to assess how your lymphoma is developing, and to decide on the best approach going forward.

If you've had a course of treatment that hasn't completely got rid of the lymphoma, you may go on active monitoring so that your medical team can monitor your health.

What is 'active' about active monitoring?

Active monitoring is a concept that doesn't always sit easily with people, and some people find it difficult to get their heads around it.

It's important to emphasise that active monitoring is not 'doing nothing'.

Medical teams should explain it in detail and clinical nurse specialists (CNSs) are really important when it comes to communication around active monitoring.

CNSs are often the first port of call for people if they have questions or want to discuss any worries they may have. For some people, their GP may be a key part of their care team, as some GPs are happy to do blood tests, interpret the findings and communicate with the haematology team.

Active monitoring is generally recommended when the benefits of having regular check-ups with your medical team outweigh the risks of being given toxic drugs that may not improve your health. This means that you avoid unnecessary treatment and its side effects for as long as possible.

Whilst on active monitoring other risk factors, such as blood pressure and cholesterol levels, will be monitored.

It is helpful to get family, friends and carers involved. They are often the first

people to notice a change in you, such as a loss of appetite, reduced energy or weight loss, all of which would be a reason to talk to your medical team.



At first, I found it pretty hard to get my head around it. Speaking to people at Lymphoma Action Support Groups has been invaluable. Many have been going through it for years, and their insight really helped. Russ (pictured opposite) on active monitoring

When is active monitoring recommended?

Having an accurate diagnosis is critical to getting the right individual treatment plan. Your medical team will look at a range of clinical variables – including symptoms, blood count and the results from blood and bone marrow test, if performed.

My clinician felt active monitoring was the best approach for me because of the size of the lymph node, the fact that it is just in the stomach and it isn't affecting my lifestyle. I am physically fit and well and I still run and exercise. They explained that while things are stable and I feel well, it's best to leave well alone.

Zoe, diagnosed with follicular lymphoma in 2021



Your medical team will also look at the results from molecular and other sophisticated tests.

Clinicians use this information to assess those people at a higher risk, whose lymphoma is more likely to progress and therefore need treatment sooner rather than later. Active monitoring may be recommended for those at a lower risk as their lymphoma is less likely to progress and need treatment. It is a very individualised assessment.

Individual blood cancers have national and international guidelines. Active monitoring is a recognised pathway within these guidelines, which include how to make an accurate diagnosis, how to accurately assess the risk to a patient and how to decide on active treatment versus active monitoring.

How can I be pro-active?

Although the principles of active monitoring are similar across the range of blood cancers, it can vary depending on your type of lymphoma. For example:

- If you have chronic lymphocytic leukaemia (CLL) then blood tests are one of the best indicators in monitoring your lymphoma.

- If you have a low-grade non-Hodgkin lymphoma (LGNHL), such as follicular lymphoma or marginal zone lymphoma, your medical team will be looking for changes, such as your wellbeing, lumps and bumps, weight loss, night sweats.

For LGNHL, changes in these symptoms are more important reasons than the results of blood tests in deciding whether to bring an appointment forward or to indicate that a scan is needed. This is because LGNHL blood tests can be normal, even if the disease is progressing.

It is important for people to understand their condition and be engaged in their own health. Clinicians rely on people reporting changes in their health, and people should be aware of potential symptoms and problems to look out for (see end of article). It can be useful to note any symptoms – in a diary, on a chart or an app – to help you to detect if symptoms are worsening. Having said that, it is important not to be too obsessive either – over time most people find a happy medium.

Am I being seen often enough?

People vary enormously; some like the reassurance of going to hospital frequently, while others view less frequent appointments as reassuring.

Clinicians try to keep hospital visits and blood tests to a frequency that allows them to detect changes in your health. However, no matter how often you are having appointments, it is important to emphasise that if you have any concerns between appointments, you should get in touch with your medical team. The chance is that if something is going to change, it will happen between appointments.

In rare cases, there can be a rapid significant change in someone's health, but in most cases where someone is on active monitoring, change is gradual. Your medical team will tend to arrange hospital appointments based on how they understand your disease is behaving. After diagnosis, or after completing treatment, you are likely to be seen more frequently.

Initially, I had appointments at the hospital every 3 months, and then every 6 months, when I have blood tests. I have three support nurses who I can contact between appointments if I have any concerns.

This might change as your medical team have a better understanding of your lymphoma, and they might feel that more time between appointments is appropriate.

How often should I check for symptoms?

Symptoms are likely to come on gradually so you don't need to check for symptoms daily, but it is important to monitor how you are feeling over time. Many symptoms of lymphoma, such as fatigue or weight loss, are quite general, so it is difficult to know what is significant and what is not. Remember, those around you might be in the best position to flag up any concerns about your health. However, if you have any worries call your CNS about the symptoms you are experiencing, particularly those listed at the end of this article. They will be able to reassure you, or liaise with your consultant to bring an appointment forward if needed. It does not rest on your shoulders to feel you have to know what is urgent and what is not.

If there is something you are concerned about do not wait until your consultation. Get in touch. It may not be an issue, but do not wait.

How long does active monitoring last?

Clinicians should set out the factors that will lead to a change in the management plan for a individual patient. Generally, when a person starts active monitoring, it can last as long as there are no changes that mean an alternative approach is needed. So it is important to know what changes might trigger intervention.

There are people whose lymphoma stays stable for years or decades and many that will never need treatment at all. Clinicians cannot predict who those people will be, but this might change as knowledge improves.

What can family, friends and carers do help?

There are many ways to support an individual with lymphoma. One of the most important is to understand active monitoring, and don't be afraid to ask questions. The clinical nurse specialist is a good person to provide information. Alternatively, you can contact Lymphoma Action. Some people want to know lots of information, and others just enough for their circumstances. This is understandable, and you can support the person by helping them find out what they need to know.

Many people struggle to come to terms with active monitoring and a clinical psychologist may be helpful. Your health team should be able to refer you to places where you can get help.

Symptoms of lymphoma

The most common symptoms of lymphoma are:

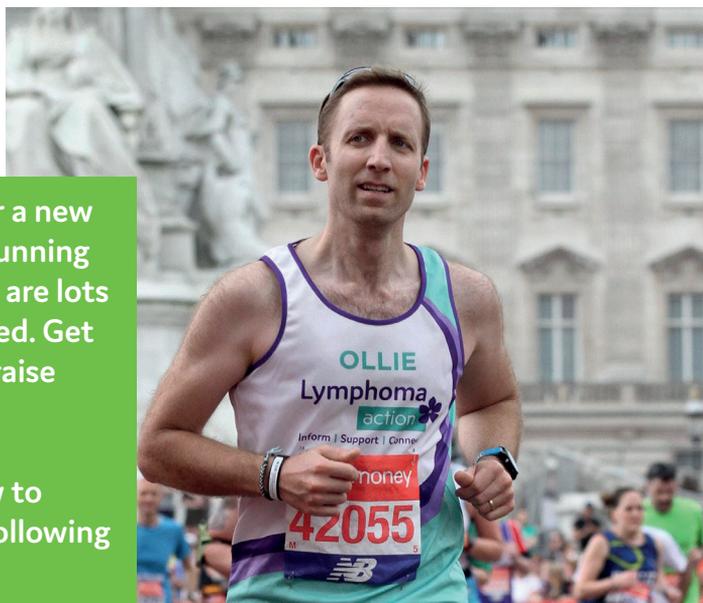
- **Swollen lymph nodes** – lump or lumps, usually in the neck, armpit or groin. They are usually painless.
- **Fatigue** – increased fatigue where you feel exhausted for no obvious reason or feel washed out after doing very little. It is not the same as normal tiredness; fatigue is overwhelming and doesn't usually improve after sleep or rest.
- **Unexplained weight loss** – losing a lot of weight quite quickly without trying to.
- **Sweats** – most commonly at night and drenching such that nightclothes and bed sheets become wet.
- **Itching** – without a rash, which can be troublesome.
- **Loss of appetite.**
- **Persistent infections.**
- **Just not feeling right.**

To watch the full webinar, including the experience of people living on active monitoring, go to lymphoma-action.org.uk/wellbeing-videos#LivingAM

Take on a running challenge for #TeamLymphoma!

Whether you're looking for a new challenge this autumn or running is already *your thing*, there are lots of ways you can get involved. Get your trainers on, and help raise vital funds for us!

Contact us to find out how to secure your place for the following fantastic events.



Hackney Half Marathon – Sunday 26 September 2021

This is one of the flattest, fastest and freshest half marathons, and the one that shows off East London at its best!

Hackney knows how to 'party' and you too can join the carnival as the streets are lined with supporters and live entertainers.

lymphoma-action.org.uk/hackney-half-marathon

Loch Ness Marathon – Sunday 3 October 2021

Keep your eyes peeled for a famous local!

This is quite possibly one of the most stunning marathons in the world, which follows a spectacular point-to-point route alongside the world famous Loch Ness. Why not make a Highland weekend of it and come with family or friends?

lymphoma-action.org.uk/loch-ness-marathon



Virtual London Marathon 2021 – Sunday 3 October 2021

This year the London Marathon will be the biggest virtual marathon staged anywhere in the world!

To take part you just have to complete the 26.2 miles within 24 hours on Sunday 3 October - so it's your run, your way! This means you can take it at your own pace and run or walk to receive that coveted finisher's medal. We have secured 35 places and would love for you to join our team as we celebrate our 35 year anniversary.

lymphoma-action.org.uk/London2021

Royal Parks Half Marathon – Sunday 10 October 2021

Experience the best of London's Royal Parks

The stunning route includes Hyde Park, Green Park, St James's Park and Kensington Gardens, with magnificent views of the capital city and historic landmarks.

lymphoma-action.org.uk/RoyalParks

Dublin Marathon – Sunday 24 October 2021

The illustrious Dublin Marathon now features in our 2021 running portfolio

Known for its relatively flat course, take in the iconic landmarks as you run through the historic streets of Ireland's capital.

lymphoma-action.org.uk/dublin-marathon

Jamie, in *Bridgerton*

Getting back to where I was

You may know actor Jamie Beamish; most recently he has played Nigel Berbrooke in *Bridgerton* and Ciaran in *Derry Girls*. Here he explains how his diagnosis of lymphoma gave him a different perspective on life.

I was diagnosed with Hodgkin lymphoma in 2007

I was 30 and playing Roy Keane in the musical comedy, *I, Keano* in Dublin. Acting on stage can be physically demanding, with seven or eight performances a week, so I had been exercising beforehand and was losing weight in preparation for my role in the show.

I noticed a painless lump on my collarbone, which felt rubbery, so went to see my GP. He thought it was an infection and the lump was an inflamed node. However, a few weeks passed and it was rubbing and wasn't getting any smaller, so my GP referred me for a chest X-ray. This revealed a shadow on my chest; that was the start of numerous tests.

It was the day after the opening night of *I, Keano* that I had an MRI scan and a biopsy taken from the inflamed node on my neck. I was diagnosed with classic Hodgkin lymphoma, stage 2B (the B indicates that I had symptoms). Night sweats had just started, I had the lump, I had lost weight and was itching, but didn't think too much about it. The symptoms were there, but most of them I could explain away.

It wasn't difficult to be on stage. I was scared about the lymphoma, but acting gave me something to focus on for a few hours each evening

After diagnosis I continued working, as it would be a few weeks before treatment started. Acting was something I held on to.

I was reading up about Hodgkin lymphoma and it all sounded scary, so getting lost in the show for a few hours each evening was brilliant. The lymphoma wasn't making me feel ill, although I did feel ill later – because of the treatment. Thinking about it, I'd probably had the Hodgkin lymphoma for some time; certainly before I started working on the show.

I was upfront with the cast about the diagnosis and everyone was worried and sympathetic. Dark humour broke the ice and helped us through, with the suggestion that *I, Keano* should be changed to *I, Chemo*!

I've had to do all sorts of things to my hair when acting, so losing it wasn't a problem

I had six rounds of ABVD chemotherapy over six months. Back in 2007, antiemetics weren't as effective as they are now, so it was a bit of a rough ride. It made me very sick.

Although I normally live in London, *I, Keano* was on in Dublin. Therefore I was diagnosed and treated at home in Ireland. It made such a difference to be with my family and have my mum and grandma really looking after me.

My acting work stopped, which was a real blow

As soon as treatment started, I had to stop the tour of *I, Keano*. I had two more plays lined up, but I couldn't be in them, and I remember feeling devastated that they were going ahead without me. But then my haematologist told me that my bone marrow biopsy was clear, and everything was put into stark perspective. My health was what really mattered at that time and although I was disappointed that my acting work stopped, I knew there would be more roles in the future.

At the end of 2007 I went into remission, and was followed-up with regular check-ups. In the summer of 2009, a CAT scan revealed the lymphoma was back.

Going through it was tough, but facing it again with relapse was much tougher

By now I was 32 and relapse felt such a blow. My haematologist explained that they planned to do an autologous stem cell transplant (ASCT) using my own stem cells, with the aim of curing my lymphoma. Those words were heartening.

Once again, it all happened in the midst of working. I was in a play at the National Theatre, London, and also had a small part in the film *Robin Hood* which was directed by Ridley Scott and starred Russell Crowe. I was due to start treatment, so my agent spoke to the producers explaining I would need to pull out as they couldn't guarantee I would be well enough. I had accepted the effect on my work by this time, but was shocked to hear that they still wanted me to be involved in *Robin Hood*. Apparently, Ridley Scott had heard about my diagnosis and said that if I was well enough, he wanted to have me on set. It was an amazing gesture, given I had a small part, but he wanted to help someone in a bad situation. It was a huge boost at the time.

I was having ICE chemotherapy before harvesting my cells for the autologous stem cell transplant. I had told my treating team about the possibility of still being in *Robin Hood* and they planned my treatment so that I was at my best when my part was due to be filmed. It was such a big thing everyone was doing for me, but they said they were delighted to be able to make this happen. A year later, it was a thrill to take my grandma to see the film.

The transplant was fine. It was after that I got sicker

The transplant itself was fine – almost a non-event after everything else – it was after the transplant that I got sicker.

I recovered more quickly than I thought and after three weeks, they were talking about sending me home. I felt nervous about leaving the hospital environment, where I had been in isolation with people gowned up to protect me from germs. Now I was heading home to be amongst people again. In reality, it was once I had got home that the recovery started. The illness never made me sick, but the treatment did. It was tough but really worth it, especially looking back 12 years later.

When you are ill you never think you will be better again

When you are small and ill you think you will never be better again. Even with something like a cold you forget within a few days what it felt like to be well. Because it was an extended period of recovery it was tricky. Will I be the same? Will I be able to do the things I did before?

I tried to run before I could walk, but bit by bit things built up again. I love what I do, but this illness stopped me doing what I love doing, as well as other things in life. For me it was all about getting back to where I was. I got to appreciate it more.

Playing a hittable baddy in Bridgerton has been great fun

When I got the script for *Bridgerton* it looked like a great project, but I thought I would be unlikely to get the part as they were looking for an Englishman, while I am Irish and sound distinctly Irish. However, I sent in a tape and got the offer to play Nigel Berbrooke, who's like the villain in the first two episodes.

The scale of the costume fitting warehouse made it clear that this was going to be a major production, and the amazing locations around England were fantastic. Being in *Bridgerton* was amazing and great fun - and I have really enjoyed all the furore that it has caused!

To listen to Jamie's podcast, go to [Lymphoma Voices at lymphoma-action.org.uk/Voices](https://lymphoma-action.org.uk/Voices)



Jamie in
Derry Girls

Your guide to wellbeing

Thinking about wellbeing can be challenging. We often think that wellbeing means feeling good all the time, but even without lymphoma, daily life may have many challenges. Wellbeing is about balancing three things: having the skills and resources to manage challenges, being able to focus on the things that matter to us most, and being kind and compassionate to ourselves so we can live well.

Finding this balance can be tricky. Our brain likes to be 'better safe than sorry', so when we are faced with situations that are worrying, or make us feel low or anxious, it automatically switches into a 'safety mode' that can feel like being hijacked. Safety mode has just three settings: fight, flight or freeze/flop. This process is automatic and floods your body with adrenaline and cortisol to get you to safety quickly. But in 'safety mode' you can't think about what would help or what you need to do. There are different signs that tell us when we're in 'safety mode', including physical symptoms or having a very busy brain.

Signs of a busy brain are:

- worried thoughts
- 'should' and 'must' thoughts (I should have done this, I must do that)
- withdrawing or isolating
- struggling with memory or concentration
- being short tempered
- feeling tired but wired
- feeling exhausted.

It might be physical symptoms that alert you to being worried. A racing heart, sweating, stomach churning, tunnel vision, lack of energy, and snappiness, are all key indicators. The ideas on the following pages are aimed at helping you to get back control.

A thought diary can help you to spot and explore signs and patterns: things that trigger low mood or anxiety and things that improve your mood or manage worry (see ideas on pages 18 and 19). Often we think are doing nothing, but if you keep an activity diary for a couple of days you may well see that you are probably achieving far more than you think. Along with the wellbeing diary (page 18), these tools can help you to plan, and find the recharge points and balance that are so important for wellbeing.

Wellbeing diary

Finding your wellbeing balance can be a challenge when you are affected by lymphoma

A wellbeing PACE-ing diary can help you to notice the things you are doing that help, the things you might want to do more of and areas where you might need some help. You might notice that many things you do fall into a number of the areas.

PACE stands for Physical and health, Achievements, Connections and Enjoyment.

Physical and health	Went for a walk, had 8 hours sleep
Achievements	Baked a cake, helped kids with homework
Connections	Attended a support group, had coffee with a friend
Enjoyment	Read a book, went out for lunch, enjoyed the garden

Monday

Physical and health
Achievements
Connections
Enjoyment

Tuesday

Physical and health
Achievements
Connections
Enjoyment

Wednesday

Physical and health
Achievements
Connections
Enjoyment

Thursday

Physical and health
Achievements
Connections
Enjoyment

Friday

Physical and health
Achievements
Connections
Enjoyment

Saturday

Physical and health
Achievements
Connections
Enjoyment

Sunday

Physical and health
Achievements
Connections
Enjoyment

My wellbeing plan

When you are feeling very stressed, low or upset, it can be hard to remember what you have found to be helpful, and who is there to support you

Making a note of these things and keeping it somewhere that's easy to find (perhaps a photo on your smart phone or a printed copy) can make it easier to recover your wellbeing balance at these times and decide what to do next.

What's happening now?

How I hit the pause and reset button is:

What helps to calm me or lift my mood is:

The people who help or support me are:

Some helpful contact numbers or websites are:

Things that recharge me are:

Ideas to help you pause

Rectangular breathing

You can do this in just a few seconds.

- Notice any rectangle around you (it could be the TV, a window, a book).
- On the short side of the rectangle, **take a normal breath in.**
- On the long side of the rectangle **take a long breath out** (maybe 3 seconds or more).
- **Feel your shoulders drop down.** This gives a message to your brain that you're not fighting any more.
- **Repeat five times.**

Focus on your surroundings

Think about other things, by focusing on your surroundings. Consider:

- 5 things you can see
- 4 things you can hear
- 3 things you can touch
- 2 things you can smell
- 1 thing you can taste.

Explore what worked before

It might help to write a list of what helped you before you had lymphoma.

What made you feel better if you were worried about something?

It may be going out for a walk, a run or a swim, gardening or simply enjoying the sun on your face.

To do lists

Lists can help with planning and bring a real sense of achievement. By crossing things off, you appreciate how much you have done. You can focus on the day, the month or even the year.

Four little questions

Ask yourself these questions to help you identify what is causing you worry and anxiety:

- **What can I notice in my body?**
(Heart racing, exhaustion, tension/pain, stomach churning)
- **What's going through my mind?**
(What if I have to start treatment, I can't do anything, things will never be normal)
- **What am I doing?**
(Being snappy, withdrawing, doing too much, ruminating)
- **How do I feel emotionally?**
(Scared, sad, lonely, angry, frustrated, worried)

Take your attention away from the threat

Have something else to focus on.

- Put something in your pocket, like those little yellow stretchy men or a pebble.
- Put an elastic band on your wrist and give it a little snap; it will give you something else to focus on.



Bridges of Britain is back!



We're delighted to be bringing back our Bridges of Britain walk for 2021.

This is a family friendly event all about you – **Your Walk, Your Way** – you just have to complete a 7-mile walk which includes walking over a bridge. Put a date in your diary for **Sunday 26 September**. Wherever you are in the UK, you can get involved!

As well as 2021 being our 35th anniversary, this event is taking place during Blood Cancer Awareness Month, so we want to see as many of you as possible out there walking in your purple T-shirts. And as this event is arranged completely by us, every penny you raise in sponsorship goes directly to support people affected by lymphoma.

It will be rewarding, fun, and 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'll 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. There is also a prize for the most bridges crossed!

lymphoma-action.org.uk/BridgesWalk

Staging of lymphoma

'Staging' is the process of working out which parts of the body are affected by lymphoma. This is important in order to give information on prognosis and for deciding on the best treatment. The tests and scans people have when they are diagnosed help doctors to work out the stage of their lymphoma.

The lymphatic system runs throughout the body to enable our immune system to protect it. White blood cells, or lymphocytes, carried in the lymphatic system circulate so that they can respond to infection or inflammation wherever it occurs in the body. It is common for lymphoma to be in several areas when it is diagnosed, which may be termed 'advanced stage' lymphoma.

Other types of cancer may 'spread' to lymph nodes, but lymphoma cells can often be found in other areas of the body because they normally circulate throughout the body.

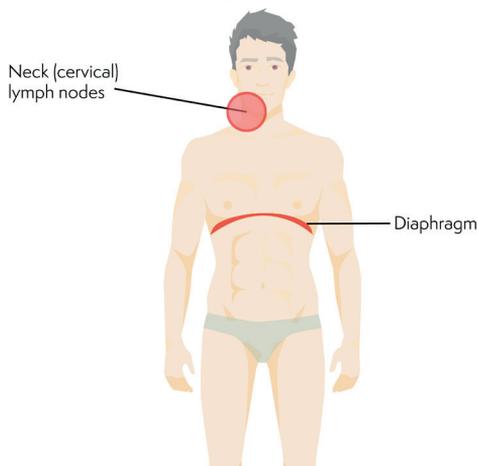
Staging lymphoma is important in helping medical teams plan the most appropriate treatment, as different stages need different types and combinations of treatments. Advanced stage lymphoma can be treatable, and depending on the exact type of lymphoma, it may be curable or controlled for a long time.

Staging is the same for Hodgkin and non-Hodgkin lymphomas, with a few exceptions:

- non-Hodgkin lymphoma in children
- chronic lymphocytic leukaemia (CLL)

Staging of Hodgkin and non-Hodgkin lymphoma in adults

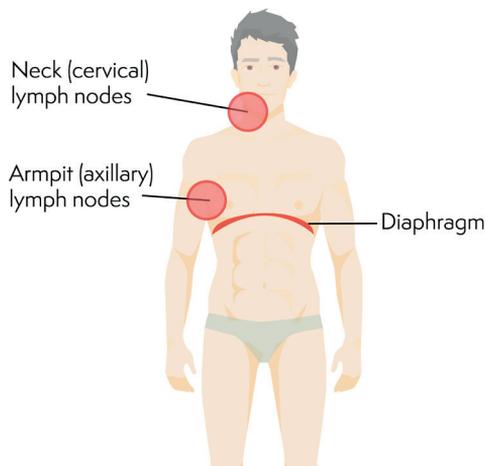
There are four stages of lymphoma, numbered 1 to 4 or in Roman numerals, I to IV.



Stage 1:

Only one group of lymph nodes affected

Lymphoma is in only one group of lymph nodes (glands) or site (for example salivary gland, stomach, orbit). This can be anywhere in the body.



Stage 2:

Two or more groups of lymph nodes affected

Lymphoma is in two or more groups of lymph nodes or sites. These can be anywhere in the body, but on the same side of the diaphragm (the muscle separating the chest and the tummy).

- Waldenström's macroglobulinaemia
 - skin (cutaneous) lymphomas.
- Read about how these lymphomas are staged at lymphoma-action.org.uk/Staging

Letters or numbers after your stage

The letter 'A' after the stage means none of the following 'B' symptoms are present:

- unintentional significant weight loss
- drenching night sweats
- fevers (temperatures above 38°C).

The letter 'B' means the person has one or more of these symptoms.

The letter 'E' is for 'extranodal', and means lymphoma started outside the lymphatic system - for example, in the digestive system or in the salivary glands. As the spleen and the thymus are part of the lymphatic system, lymphoma in these organs is not 'extranodal'.

The letter 'S' after the stage means there is lymphoma in the spleen.

'Early' stage and 'advanced' stage

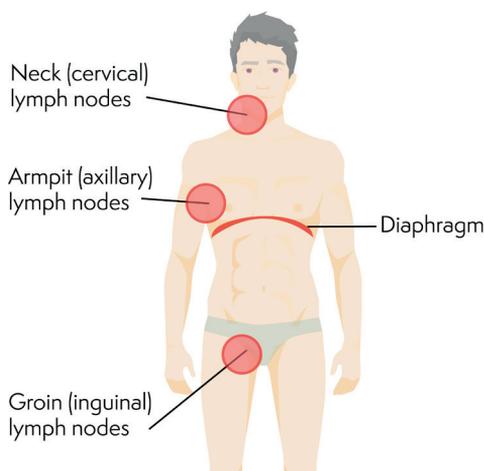
'Early' (or 'limited') stage or 'advanced' stage lymphoma is a simplified version of the staging above. 'Early' stage generally means stage 1 or 2, and 'advanced' stage means stage 3 or 4.

The difference between stage and grade

'Stages' and 'grades' of lymphoma are different: the **stage** is how much of the body is affected by lymphoma, and the **grade** is how quickly the lymphoma is growing.

- Low-grade lymphomas are usually slow-growing and high-grade lymphomas are usually fast-growing.
- Lymphoma can be high-grade but early stage, low-grade but advanced stage, or any other combination.

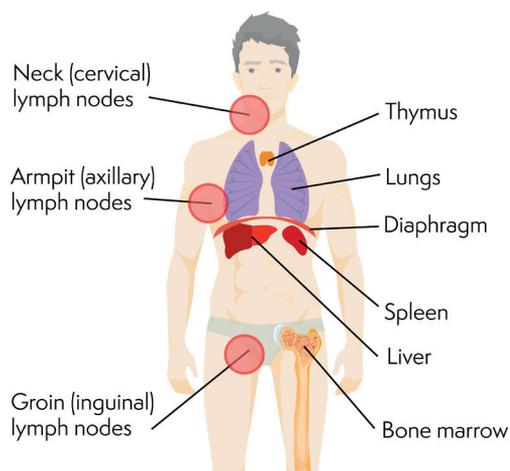
With thanks to Dr Eve Gallop-Evans, Consultant Clinical Oncologist at the Velindre Hospital, Cardiff, for reviewing this article.



Stage 3:

Lymph nodes affected on both sides of the diaphragm

There are lymph nodes that contain lymphoma, or affected sites, on both sides of the diaphragm.



Stage 4:

Lymphoma either in organs outside the lymphatic system or in the bone marrow

Lymphoma has spread to the bone marrow or at least one organ outside the lymphatic system (for example the lungs, liver or solid bones).



Alan's story

In 2009, at the age of 67, I had just come back from holiday. Despite being tanned, which makes people look well, I was struggling with pain in my stomach and had a rash around that area.

I had also lost a noticeable amount of weight during my trip. I went to see my GP who thought I had shingles and gave me antivirals. Unfortunately the pain didn't go away.

I went back to my doctor who had a young locum training with him, so he asked her to examine me. She thought I had an enlarged spleen, so it was suggested I have blood tests carried out straightaway. Within a day I received a phone call from a consultant haematologist asking me to go to see him.

My spleen, instead of being tucked safely under my ribs on the left side, stretched right across my abdomen. This, along with the night sweats I was now experiencing and loss of weight was flagging a serious problem to the haematologist. I have to admit, I wasn't feeling my best by now.

At first leukaemia was suggested, but after bone marrow samples were taken and further tests were done, I was diagnosed with indolent B-cell non-Hodgkin lymphoma, stage IVB.

It's easy to put symptoms down to just getting older

I was examined by a leading splenectomy specialist, and there was talk about having my spleen removed. After researching into the spleen, I realised if it is working properly, it provides about 30-40% of the immune system, so I was keen to hold on to it. Fortunately a splenectomy was avoided and, although compromised, it is still part of my immune system.

Chemotherapy started in February 2010 with R-CVP (rituximab, cyclophosphamide, vincristine and prednisolone), which was successful without too many nasty side effects. I started off partially bald anyway, so losing some of my hair didn't worry me. On a positive note, my spleen reduced to near normal size. What troubled me most at that time was feeling so sick. I felt really rough for quite a bit of the time, but felt fortunate not to have the terrible ulcers that other people struggle with.

I was placed on active monitoring (watch and wait) without any further medication until 2016 when my spleen started to enlarge again and my red blood cell count reduced.

For my second batch of chemotherapy I was given rituximab and bendamustine which thankfully was again successful, with fewer side effects.

The experience did not seem as harsh as the previous chemotherapy and I was particularly relieved that the anti-sickness drugs given to me seem to have improved enormously. I am now back on active monitoring (watch and wait).

I realise, in retrospect, the lymphoma was probably present in my body some years before I retired; but I had thought that the reduced energy and drive was just because I was getting old.

Since retirement, and whilst self isolating during chemotherapy treatment, I started writing a book. It was published in 2019 and is entitled *A Working Life* by A.F. Lodge, which looks back on some of the fascinating places I have worked during a career in the chemical engineering sector. It is part travel blog and includes countries like Russia, Bulgaria, Iran and India, experienced in very different times over the past sixty years. Ironically, the penultimate job I worked on was validating a plant in Spain built to produce rituximab, the monoclonal antibody included in my treatment. This, along with my wife and the wonderful staff who have treated me and helped to keep me alive, I owe a big 'thank you'.

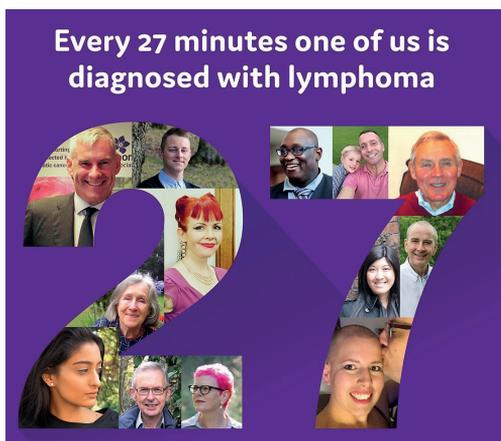


To my wife and the wonderful staff who have treated me and helped to keep me alive, I owe a big 'thank you'.

September is Blood Cancer Awareness Month

Every 27 minutes, one of us is diagnosed with lymphoma. It's the UK's fifth most common cancer, but is not well known and the signs can be overlooked.

While all our work helps to raise the profile of lymphoma, we have a specific focus on awareness raising during September and we would love to see lots of you get involved!



Share the symptoms

Order or download our symptoms posters and postcards and display them at your local GP surgery, supermarket, place of worship, library, community centre, workplace or even your own front window.

Support World Lymphoma Awareness Day - Wednesday 15 September

Engage with our social media posts on World Lymphoma Awareness Day to be part of a global message - the more you share, like and comment the further the messages will travel and the higher the profile will be raised!

Join 27 in 27

By taking part you will not only help spread the important message that **someone is diagnosed with lymphoma every 27 minutes**, you will also raise vital funds to support our work.



Find out more and sign up at: lymphoma-action.org.uk/Awareness

Here's some ideas for how you can raise your £27 to help us provide much needed support to people affected by lymphoma:

- Look in pockets and old bags to collect lost, loose change.
- Offer to walk a friend's dog for a donation.
- Sell an item of clothing you no longer wear on an online auction site.
- Wash someone's car – or 27 cars! – for a donation.
- Host a BBQ for your friends for a small entry fee.
- Bake cakes or biscuits and 'sell' them in return for a donation.



Or why not get sponsored to do something?

- Cycle 27 miles during a month (that's just four 7-mile rides!)
- Walk to school or work 27 times.
- Swim 27 lengths or widths in your local pool.
- Run a mile a day for 27 days.
- Do 27 minutes of exercise a day.

How your £27 will help

- £27 will fund: A call to our dedicated helpline, enabling our experienced team to support anyone affected by lymphoma, including family and friends.
- £270 will fund: Adding 4 clinical trials to Lymphoma TrialsLink - to help people find clinical trials that may be suitable for them.



I don't let my lymphoma define me and how I feel about myself

Harriet talks about the importance of not giving up after 17 years of failed treatments and misdiagnosis for her exceptionally rare T-cell skin lymphoma, Hypopigmented Mycosis Fungoides (HMF). She explains how Lymphoma Action helped her to come to terms with her diagnosis.



I am sharing my story for several reasons. Firstly, I hope that I can play a small part in raising awareness of my exceptionally rare cutaneous (skin) lymphoma. Secondly, I hope that it encourages others to not give up when you know something is not right with your body, and you're still not getting the help and the answers that you need. Finally, I wanted to share how Lymphoma Action helped me find the answers that I was looking for, which has enabled me to move forwards positively and to fully come to terms with my skin condition, one that I will be living with, and managing, for the rest of my life.

I first realised something wasn't right with my skin when I was 14 years old. I was sunbathing on holiday and I noticed numerous dry, flaky, scaly patches which didn't tan, and which felt and looked like parchment or cigarette-paper. No amount of cleaning, scratching, scraping or moisturising made them go away.

Initially, they were across my stomach, lower back and buttocks. However, over the years they have spread slowly over a much larger surface area of my body. Right now, they are across the top of my thighs, buttocks, trunk, underarms, arms, and breasts. My pale white skin and certain lighting makes the patches difficult to detect with a quick glance, but whenever I tan under natural sunlight the patches on my skin don't. This means my skin then has an alarmingly obvious mottled appearance that is startling to those who are unaccustomed to seeing it.

Comments from strangers about my skin motivated visits to GPs and dermatologists. Repeatedly, I was misdiagnosed and treated for a variety of different skin conditions: eczema, ichthyosis, tinea versicolor, vitiligo and dry skin. No treatment had any positive effect, the doctors didn't have any answers, and there was no follow-up. This period of uncertainty and the failure of treatments was exhausting and upsetting.

After 17 years of looking for answers and getting nowhere, I was close to giving up entirely. After yet another comment from a well-meaning stranger during a sunny holiday in 2019, and with some loving encouragement from my husband, I found the strength to pick myself up and persist with the elusive task of finding out what was wrong with my skin.

Thankfully, I was finally referred to the right specialist and was told that I have a T-cell lymphoma called Hypopigmented Mycosis Fungoides (HMF). Despite the serious nature of this condition, when I was told about it I felt an enormous weight lift off my shoulders. Looking back, not being diagnosed for so long significantly affected my self-esteem and my mental health.

I immediately started treatment: steroid cream and five months of phototherapy treatment. Unfortunately, after a brief period of complete remission, my patches came back. I'm on active monitoring (watch and wait) and I will have regular courses of phototherapy to manage and control my condition for the rest of my life.

My consultant was excellent, but I was left with unanswered questions, and decided to find out more information myself. I knew my condition was incredibly rare but I was surprised at how little information, let alone up-to-date medical studies, were available. When I found the Lymphoma Action website I was relieved to find a wealth of information. Along with the personal stories of others, this really helped me to come to terms with my condition.

I very quickly became more informed and was able to get the closure I needed to move forwards positively with my life.

I no longer felt alone and my anxieties significantly lessened. The importance of finding the answers that I needed was life-changing. I feel empowered not to let my lymphoma define me and how I feel about myself. I am determined to live well with it, and to not let it live my life for me. Now, when I look in the mirror I don't feel confused, upset and sad. My focus on what's important in life has sharpened. I am making better choices, and in some ways I feel more alive than ever.



This is where my story ends. It's time for me to get back on-board the 'train of life'. But before I go, it is my sincerest hope that my 17-year struggle to find answers and get the right treatment encourages anyone who is similarly struggling to keep going. It is so important if you feel that something isn't right with your body to trust your gut, to keep going, and to not give up on yourself. As downhearted as you may feel about the likelihood of getting there now, if you keep striving to find the answers you will be much more likely to eventually get the right diagnosis and help that you need. If that message resonates with even just one person who needs to hear it, then I'd like to think that my brief stop at this station, during the course of my life journey, has been a few minutes well-spent.



Clinical trials update from the ASH conference

The American Society for Hematology (ASH) annual conference took place virtually in December 2020. In March, haematologists in the UK discussed the most important research presented at ASH.

Hodgkin lymphoma

The **AHL2011 study** looked at a PET-guided approach to treatment for people with advanced stage Hodgkin lymphoma. People who took part in the trial either had six cycles of escalated BEACOPP chemotherapy, or two cycles of escalated BEACOPP followed by a PET scan. Depending on the results of the scan, they then either continued with escalated BEACOPP or switched to a lower intensity regimen (ABVD). Long-term outcomes were excellent in all treatment groups, with no difference between the PET-guided approach or escalated BEACOPP. PET-guided treatment had a significantly lower impact on fertility in both men and women: an important consideration for some people with Hodgkin lymphoma.

The **NIVAHL trial** compared first-line treatment of four cycles of nivolumab (a type of targeted treatment called a 'check-point inhibitor') plus AVD chemotherapy with a sequential regimen of four cycles of nivolumab followed by two of nivolumab plus AVD followed by two of AVD alone. Everyone in the trial also had radiotherapy. Both combined and sequential treatment with nivolumab and AVD was very effective and provided durable responses to treatment. This suggests that nivolumab is a promising option for people with Hodgkin lymphoma who haven't been treated before. The question is whether using drugs like nivolumab can enable less chemotherapy and radiotherapy to be used.

A US study looked at the potential of using brentuximab vedotin (an antibody that sticks to Hodgkin lymphoma cells and carries a chemotherapy drug straight to them) for first-line treatment of people over 60 with Hodgkin lymphoma. Older people tend to have poorer outcomes than younger people.

The trial studied brentuximab vedotin on its own or combined with other drugs. Response to treatment was excellent in all groups but the response lasted longer in people who had combination therapy. The combination of brentuximab vedotin plus dacarbazine was particularly interesting, combining good efficacy with a favourable side effect profile.

Another US trial investigated a combination of pembrolizumab (another checkpoint inhibitor) plus chemotherapy with gemcitabine, vinorelbine and doxorubicin (GVD) in people with relapsed or refractory Hodgkin lymphoma. Treatment was well tolerated and the response rate was very high, although the trial was small. A larger trial is needed to confirm whether or not this is an effective second-line treatment for Hodgkin lymphoma.

A long-term follow-up study reported on the risk of cardiac late effects in adolescents and young adults treated for Hodgkin lymphoma. After 15 years of follow-up, around 6 in 100 young people treated for Hodgkin lymphoma had experienced heart problems compared to just over 2 in 100 young people who had not had treatment for Hodgkin lymphoma. The risk was higher for people who had radiotherapy to the chest as well as chemotherapy than in people who had chemotherapy on its own. These results are important to help develop effective monitoring and screening for late effects of treatment.

T-cell lymphomas

T-cell lymphomas can be difficult to diagnose and treat. Despite considerable efforts to improve treatments there has been little progress. The **ECHELON-2** trial was the first randomised study to confirm that adding brentuximab vedotin to CHP (CHOP without vincristine) improved overall survival over CHOP chemotherapy. Brentuximab vedotin + CHP improved overall survival best in a type of peripheral T-cell lymphoma called systemic anaplastic large cell lymphoma (sALCL). The 5-year follow-up of the ECHELON-2 trial showed that it continues to provide long-term benefits. Interestingly, in the minority of people who experienced a relapse, treatment with brentuximab vedotin on its own produced promising clinical responses independent of whether brentuximab vedotin had been given before.

Other potential new treatments are being developed for T-cell lymphomas.

A phase 2 trial investigated the impact of adding a chemotherapy drug called azacitidine to standard treatment in people with peripheral T-cell lymphomas. The early results were encouraging, demonstrating promising efficacy and being generally well tolerated. It is being studied further in a trial called **ORACLE**, in people with relapsed or refractory T-cell lymphomas.

A new treatment option called PLM60 was studied in a phase 2 trial of people with a variety of different relapsed or refractory T-cell lymphomas. Responses to treatment were encouraging, especially in people with angioimmunoblastic T-cell lymphoma (AITL) or extranodal NK/T-cell lymphoma (ENKTL).

Another trial looked at a new treatment called BNZ-1, which works by changing the way your immune system responds. This small, early phase trial showed that the treatment was well tolerated and showed 'proof of principle' in people with relapsed or refractory T-cell skin lymphoma. It now needs to be studied further.

Diffuse large B-cell lymphoma (DLBCL)

Although none of the trials presented at ASH are likely to change the way DLBCL is treated at present, some of them introduced new and interesting research.

A CAR T-cell therapy targeting two different proteins on lymphoma cells was tested in humans for the first time. This treatment was made using a technique called 'fresh-to-fresh' production, which allows the CAR T-cells to be manufactured faster without freezing the cells. Early data suggest the treatment could benefit people with relapsed or refractory DLBCL and might result in lower toxicity than current CAR T-cell therapy.

There were also interesting data on bispecific antibodies. These are antibodies that bind to two different target proteins: one on a lymphoma cell and one on a T cell. This allows the T cell to recognise and kill the lymphoma cell. Several bispecific antibodies are being developed to treat lymphoma. Early results are promising but they can cause a serious side effect called cytokine release syndrome. A recent trial found that pretreatment with obinutuzumab, combined with increasing the treatment dose in three gradual steps, reduced risk of cytokine release syndrome in people treated with a bispecific antibody called glofitamab. Bispecific antibodies are

likely to be a very important treatment option for DLBCL in the future.

For people with DLBCL who have not had treatment before, the **ACCEPT** trial showed that adding the targeted drug acalabrutinib to standard R-CHOP treatment produced impressive outcomes. This will be explored in more detail in a UK trial called **REMoDL-A**.

Low-grade non-Hodgkin lymphomas

The **BRUIN** trial studied a new, oral drug called pirtobrutinib in people with relapsed or refractory B-cell non-Hodgkin lymphoma or CLL/SLL. Pirtobrutinib is similar to existing treatment ibrutinib. At ASH, researchers presented early results of the trial, showing that pirtobrutinib was generally well tolerated and seemed to cause fewer serious side effects than ibrutinib. It showed promising efficacy even in people who hadn't responded to previous treatment with ibrutinib. The findings were similar in people with B-cell non-Hodgkin lymphomas and CLL. These are very early results and follow-up data isn't available yet. The trial is ongoing.

Preliminary results of the **TRANSCEND** trial of the CAR T-cell therapy lisocabtagene maraleucel showed that it had a manageable toxicity profile and promising activity in people with mantle cell lymphoma who had had at least two previous courses of treatment. Around 1 in 3 people in the trial had already had treatment with a stem cell transplant, so this might have potential in people with few other treatment options.

The **VALERIA** trial looked at a combination of targeted treatment with venetoclax, lenalidomide and rituximab in people with relapsed or refractory mantle cell lymphoma.

These treatments can produce an initial response but it isn't always maintained after treatment ends. In this trial, people stopped treatment if specialised tests of blood and bone marrow carried out at least 3 months apart both showed no signs of lymphoma (sometimes known as 'molecular remission'). Using this measure, initial responses to treatment seemed durable and stopping treatment when a person is classed as in molecular remission may be feasible.

For people with mantle cell lymphoma who haven't had treatment before, a long-term follow-up trial found that rituximab and lenalidomide can provide long-lasting remissions. Outcomes are similar to those with stem cell transplants, but the treatment is much less intensive.

In follicular lymphoma, a bispecific antibody called mosunetuzumab was generally well tolerated and produced high response rates in people who had relapsed after at least two previous courses of treatment. This could represent a new treatment approach for people who have, in the past, been difficult to treat.

Chronic lymphocytic leukaemia (CLL) or small lymphocytic lymphoma (SLL)

In first-line treatment of CLL, several trials presented results of chemotherapy-free treatment options. Long-term follow-up data from the **CLL14** trial found that fixed duration treatment with venetoclax and obinutuzumab gave a long-lasting response. After 4 years, 4 out of 5 people treated with the combination had not needed further treatment.

In the **CAPTIVATE** trial, 12 months of treatment with ibrutinib and venetoclax produced high rates of undetectable disease in the blood or bone marrow (MRD-negativity).

People who were MRD-negative after initial treatment were randomised to receive either ibrutinib maintenance therapy or placebo. In this trial, everyone who continued ibrutinib remained MRD-negative after 1 year.

In the **SEQUOIA** trial, people with CLL/SLL with a genetic mutation called a 17p deletion and who were either over 65 or not able to have standard chemoimmunotherapy treatment were treated with a targeted drug called zanubrutinib. Zanubrutinib produced durable response rates in these people.

For people with relapsed or refractory CLL, 5-year follow-up data from a trial called **MURANO** confirmed that fixed duration treatment with venetoclax plus rituximab gives longer remissions than treatment with bendamustine plus rituximab. In people who experienced a relapse, both ibrutinib (or ibrutinib-like) therapy or retreatment with venetoclax had high response rates.

Long-term follow-up of a trial called **CLARITY** in people with relapsed or refractory CLL showed that initial responses to treatment with ibrutinib plus venetoclax were durable. In this trial, people who were MRD-negative stopped treatment while people who were MRD-positive carried on. Responses were maintained even in people who stopped treatment. How quickly signs of CLL disappeared from the blood and bone marrow helped predict how long the response to treatment was likely to last, with faster 'disease depletion' being associated with longer responses.

With thanks to Dr Chris Fox, Professor Tim Illidge, Dr Graham Collins, Dr Piers Patten and Dr Stephen Robinson for reviewing this summary.

There are so many ways to keep in touch with us - and others

Since Russ's diagnosis of follicular lymphoma, he has seen no-one face-to-face. However, with many of our services being online, he was able to reach out to us, and to others, for support.

'In April 2020, shortly after lockdown, I was diagnosed with follicular lymphoma. It was explained that it was cancer and that it was treatable but not curable. Hospitals weren't open due to COVID, and both my partner and I were in shock and felt completely isolated. Where do we go from here?

I contacted Lymphoma Action who were very helpful and sent leaflets explaining my illness and how to cope with it. I also joined the Lymphoma Action UK Facebook page, which has also helped.

With the COVID-19 situation, there were no face-to-face support group meetings so I registered for the virtual support meetings. They have been so helpful. The people are really friendly, and it's good to speak to others who have lymphoma. Some have lived with it for years and others, like me, have been diagnosed recently.

The group and the Facebook page are there to pick me up, but they have also helped my partner Karen. I think people forget that loved ones are also going through a tough time and also need support. The virtual support group has been a chance for Karen to 'vent' or ask questions to people in the same situation.



Russ and Karen

I urge anyone affected by lymphoma to get in touch with Lymphoma Action. You are not alone, there are people out there to help you.'

Russ

To find out more visit lymphoma-action.org.uk/online-services-and-support

Any plans for face-to-face meetings?

'We are increasingly being asked if and when we plan to have face-to-face meetings again. During the COVID-19 pandemic we've been supporting people through online services and support and will continue to keep you connected in this way for the rest of 2021.

We know that some people are looking forward to a time they can meet face-to-face, while others prefer the virtual options. I suspect our approach, as we go forward, will be a mixture of both. We will keep a close eye on how things develop and will update you in the October issue of *Lymphoma Matters*.'

Ropinder Gill, Chief Executive

Want to speak to our helpline in another language? You can!

You can talk to us in over 200 languages through the interpreting service Language Line. To speak to us in another language, call our helpline and tell us what language you would like to talk to us in. If you can't make the call, you can ask someone to call on your behalf. We'll take your name and number, and Language Line will call you back and we can have a three-way helpline call. What you ask us will be translated by Language Line to us, and our reply will be translated back to you. The service is free and confidential.

Helpline – freephone **0808 808 5555**, 10am to 3pm, Monday to Friday.

Find out more at

lymphoma-action.org.uk/language-line

LanguageLine
Solutions®

Lymphoma Action services – here for you

Helpline – call freephone **0808 808 5555** from 10am to 3pm, Monday to Friday for information or emotional support.

Buddy Service – call the helpline (above) to ask about being put in contact with a Buddy, someone who has been through a similar experience to you.

Online support meetings – we now have regular online support meetings across the UK as well as meetings for family, friends and carers and for young people (18 to 35). Find out more at lymphoma-action.org.uk/online-support-meetings

Closed Facebook Support Group – join this popular group at facebook.com/groups/LymphomaActionSupportUK

Webinars – we host webinars on a range of topics. Find out what is coming up at lymphoma-action.org.uk/events

Videos – we have videos on various topics around lymphoma including about lymphoma, COVID-19, and wellbeing. Find out more at lymphoma-action.org.uk

Lymphoma Voices – our podcast series includes personal experiences and medical opinion. Find out more at lymphoma-action.org.uk/LymphomaVoices

Live your Life – virtual self-management workshops to help you improve your wellbeing after treatment or if you are on active monitoring. Find out more at lymphoma-action.org.uk/LYL



Do something wonderful



Please remember
Lymphoma Action
in your will.

Lymphoma
action 

Over the last 35 years gifts in wills have helped us to continue to support people to live with and beyond lymphoma and to make sure that no one faces lymphoma alone.

If you would like to discuss leaving a gift in your will, please contact us on 01296 619400 or email fundraising@lymphoma-action.org.uk.

For more information visit

www.lymphoma-action.uk/legacy