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—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.

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

Contents

04 Lymphoma Action
New name and fresher look

06 Latest news
Current news and developments

21 Clinical trials
Updates from the American Society of Hematology

24 Zoe’s story
How a diagnosis of Hodgkin lymphoma inspired her

26 Active monitoring
Talking about watch and wait

28 John’s story
Two very different experiences of lymphoma

32 Support groups and volunteering
Get involved

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- Visit www.lymphoma-action.org.uk/Donate
- Text LAUK02 and the amount you’d like to donate, eg LAUK02 £5, to 70070
- Call us on 01296 619419.
Introductions

I am delighted to have the opportunity to introduce myself as the Interim Chief Executive, but perhaps more importantly, also introduce Ropinder Gill who has been appointed the new permanent Chief Executive of Lymphoma Action.

I have been in post since February and will continue until mid August when Ropinder starts. Ropinder joins us from Peace Hospice Care where she is the Director of Income Generation.

The other introduction is of course to our new name, brand and website. We launched Lymphoma Action on 18 April and have been delighted by the response we have received to the new look and feel. Our new website should provide a much simpler experience for all users with the drop down menu on the home page allowing easy access to the most relevant information for you.

It has been a privilege to have been involved with Lymphoma Action, albeit for a short period, and I have no doubt at all that the organisation is in excellent hands and will grow the many ways we inform, support and connect in the years ahead.

Interim Chief Executive

TrialsLink and our forums are now live at www.lymphoma-action.org.uk
We’ve got a new name and a fresher look, but it’s still us. And we’re here for you.

On 18 April we launched our new name – Lymphoma Action – and our new website. Thank you so much to everyone who helped us along the way.

It’s been two years since one of our Trustees brought up a possible name change. Since then we have held workshops with our advisory groups, health-care professionals and staff, held buddy webinars, and visited as many of our support groups as possible. We wanted to get everyone involved in the change. And our new strapline sets out the way we want you to feel:

**Informed** with trusted information, endorsed by medical experts, to help and empower you to fully understand the complexities of lymphoma.

**Supported** at every step – we provide advice and reassurance, tailored to your individual experience. From symptom awareness, through diagnosis, treatment and beyond, we’re here to help. We also support doctors and nurses to deliver the best possible treatment and care.

To find out more, please visit www.lymphoma-action.org.uk
Connected to leading lymphoma expertise, and to those going through a similar experience, to make sure you’re not alone. Our new website, www.lymphoma-action.org.uk not only reflects our new look, but has been designed so you can find the information and support you need more easily:

- A dropdown box on our homepage allows you to select how you are affected by lymphoma, so you can find the most relevant information and services.
- Our events map has been improved so you can find out what’s happening locally and get involved.
- The personal stories section now has a filter so you can read about people who have similar experiences to you.

We’d love to hear your feedback, so please tell us what you think! Email your comments to communications@lymphoma-action.org.uk

To keep up-to-date with developments visit www.lymphoma-action.org.uk

I think the new name is great! It has a bit of ‘oomph’ and is much more dynamic than the old one. Mind you, the help I received back in 2010 when I was diagnosed was absolutely wonderful whatever the name! Keep up the wonderful work.

Did you know?

Our last name change was 20 years ago when the Hodgkin’s Disease and Lymphoma Association (HDLA) became the Lymphoma Association. It was also in 1998 that our website was first set up.

Lymphoma Action now has the look and feel of a charity of today.
Antibody therapy to benefit people with untreated follicular lymphoma

People in England with untreated advanced follicular lymphoma can now access obinutuzumab (Gazyvaro®) through the NHS now that the National Institute for Health and Care Excellence (NICE) has recommended it for routine use, after initially rejecting it.

NICE has recommended the drug be considered as part of first-line treatment for advanced follicular lymphoma – but only in higher risk cases. NICE’s announcement comes after the Scottish Medicines Consortium (SMC) decided not to recommend this use of obinutuzumab on the NHS in Scotland.

Rituximab in combination with chemotherapy is standard treatment for people with advanced follicular lymphoma who need to start treatment. Obinutuzumab is a newer antibody that targets the protein CD20, the same target as rituximab. Some people with follicular lymphoma have risk factors that make their lymphoma more likely to get worse soon after treatment. Obinutuzumab may be particularly effective for these people. NICE’s recommendation is that obinutuzumab should be considered instead of rituximab for people with risk factors suggesting they are at moderate to high risk.

This is welcome news as the approval gives higher risk patients more treatment options. Simon Hills, our Interim Chief Executive
NEW

National Lymphoma Awareness Week 10-16 September
We have refreshed Lymphatic Cancer Awareness Week. In the past we used the term ‘lymphatic cancer’ as many people hadn’t heard of lymphoma and we wanted to be clear that it was a cancer. But when people receive their diagnosis, ‘lymphatic cancer’ is not a term doctors use. So to reduce confusion, we are referring to it as ‘lymphoma’, and have renamed the week National Lymphoma Awareness Week.

It runs from Monday 10 September until Sunday 16 September. Find out more about our exciting plans for this year and how you can get involved at www.lymphoma-action.org.uk/Campaigning

New Trustee comes on board
We are delighted to welcome Dr Cathy Burton to our Board of Trustees, bringing with her a wealth of expertise.

Dr Cathy Burton studied medicine at the University of Cambridge. After Haematology training in London, she moved to Leeds, completing a MD in the biology of Hodgkin lymphoma and then became an Academic Clinical Lecturer in 2008.

In 2009, Dr Burton was appointed as a Consultant Haematologist at St James’s University Hospital, Leeds, specialising in lymphoma and diagnostics. In 2014 she became Clinical Lead of the Haematological Malignancy Diagnostic Service in Leeds, which serves a 6 million population and provides diagnostic services to numerous NCRI and commercial trials.

Dr Burton is heavily engaged in translational research in lymphoma trials and belongs to the NCRI Lymphoma Clinical Studies Group and Hodgkin lymphoma subgroup. She is also an active participant in the Precision Medicine for Aggressive Lymphoma consortium, a national network of diagnostic and therapeutic researchers working to develop molecular assays alongside clinical trials in aggressive lymphomas. She is an invited member of the Lunenberg Lymphoma Biomarker Consortium which is an international collaboration studying the application of biomarker analyses to clinical practice in lymphoma.

New book available now
We have just produced a brand new booklet on Active monitoring (watch and wait) for lymphoma. Our new booklet covers:

- what to expect when you are on active monitoring
- what signs and symptoms to look out for
- tips on coping with the uncertainty many people feel during active monitoring
- how to continue living your life and find your ‘new normal’.

Read or download the booklet at www.lymphoma-action.org.uk/ActiveMonitoring

Dr Cathy Burton

We look forward to working with Cathy. She will play an important role in developing our work.
Simon Hills, our Interim Chief Executive

Go to www.lymphoma-action.org.uk/Campaigning
It’s too close to call, was the verdict from the lymphoma debate at the British Society for Haematology (BSH) annual meeting held in Liverpool in April 2018.

CAR T-cells are a new type of treatment causing great excitement. Is it hype, or could this treatment offer a cure for some people with difficult-to-treat lymphomas?

At the lymphoma debate, clinicians were asked whether or not CAR T-cell therapy will become the standard of care for relapsed high-grade B-cell lymphomas within five years. Both sides of the argument were presented and clinicians were asked to vote for or against.

New treatment options are urgently needed for people who don’t respond to chemotherapy
High-grade B-cell lymphomas like diffuse large B-cell lymphoma (DLBCL) can often be successfully treated. If first-line treatment doesn’t work (the lymphoma is refractory) or lymphoma comes back (relapses), treatment can be difficult. Most people then have ‘salvage’ chemotherapy and possibly a stem cell transplant.

Options are very limited for people who do not go into remission with salvage chemotherapy, or for whom the lymphoma comes back again. It might be possible to have more chemotherapy, targeted drugs (often in clinical trials) or a donor (allogeneic) stem cell transplant. CAR T-cells could be a new treatment option.

Do they work better than the alternatives?
Research is still at an early stage,
so there isn’t enough data to show whether CAR T-cells can control lymphoma long-term. People who have a complete response to treatment (no lymphoma left) seem to have a long-lasting remission. However, only around a quarter to a half of people have a complete response. If the lymphoma shrinks but doesn’t go away completely (partial response), it seems to come back very quickly.

Whether CAR T-cells work better than existing treatments is debatable. Some trials have shown that allogeneic stem cell transplants and some new treatments could give similar response rates, but many clinicians said they find it very difficult to get a long-lasting response with these. Significantly, some people who have not responded to any other treatment have had a complete response to CAR T-cells, offering a lifeline to people who are out of options.

A key problem is speed of treatment. Lymphomas that are not under control can grow very quickly and people rapidly become too unwell for treatment. A significant proportion of people in CAR T-cell clinical trials haven’t made it to the stage where they can have the treatment, as they have needed treatment more quickly.

The manufacturing process is speeding up, but it still won’t be possible for CAR T-cells to be given to everyone.

**Are they safe?**

CAR T-cells can produce some life-threatening side effects, including a backlash by your immune system (cytokine release syndrome). Some people need intensive care for side effects so these treatments can only be given in centres that are

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**What are CAR T-cells?**

T cells (T lymphocytes) are cells of your immune system. They help your body fight infections and disease, including cancer.

Sometimes, abnormal cells can’t be detected by your immune system and build up into a cancer. In CAR T-cell therapy, your own T cells are collected and genetically modified (changed) to recognise and kill lymphoma cells.

A ‘chimeric antigen receptor’ (CAR) that recognises proteins on cancer cells is joined onto your T cells. Stimulatory domains are also added, which help the CAR T-cells to multiply and persist in your body.

The genetically modified T cells (CAR T-cells) are grown in the laboratory until there are enough of them, then they are given back to you, like a blood transfusion.

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**Find out more about the British Society for Haematology (BSH) at www.b-s-h.org.uk**
Medicine | Opinion

Knowledgeable about their possible effects and prepared to act quickly if serious side effects develop. Doctors are learning more about managing these side effects and it is notable that very few people die due to side effects. However, CAR T-cells are unlikely to be suitable for older people (75+).

**Can we afford them?**

Affordability is a big question. CAR T-cells are very expensive and difficult for most health economies to afford. However, costs might come down. There is competition – several companies are developing these treatments. The manufacturing process is also likely to improve.

NICE are currently assessing CAR T-cell treatments for use on the NHS in the UK. If they are approved for use, they will only be available in highly specialist units, at least at first, so people might have to travel to have these treatments.

**What’s the verdict?**

The opinion of the clinicians were split 50-50 when asked if these treatments will become the standard of care for relapsed and refractory lymphomas. Perhaps it is just a little too early to tell.

Development is continuing and a new generation of CAR T-cells are likely to be more effective. It is likely, however, that these drugs could transform the prognosis for some people with difficult-to-treat lymphoma. The impression was that these drugs will play an important role at some point in the future.

**Acknowledgements**

With thanks to Session Chair Dr Andrew McMillan, Consultant Haematologist, Nottingham City Hospital, for reviewing this article. Thank you also to the BSH for allowing us access to the meeting.
As an estate agent, mostly working with English people buying property in France, I had no intention of slowing down, despite being 63.

Early in 2016, I noticed a lump growing on my jawline. I didn’t think much about it as I thought it was just probably a fatty lump, like the sort that sometimes comes with age. It wasn’t painful, but it was a bit of a nuisance. I mentioned it at a dental appointment and he suggested I see my GP. I left it a few months, but around September 2016, I decided to go to my doctor. He referred me to an ear, nose and throat (ENT) specialist.

I had an ultrasound scan, which was inconclusive, so an MRI scan was organised. I saw the ENT specialist again, who said I would need to have the lump removed. Looking back, I now realise this was a biopsy, but in my mind they were just taking the fatty lump away.

I was called in and told I had lymphoma. Suddenly my world collapsed. I had heard of lymphoma as one of my friends in the UK had been treated for it three years beforehand. But a bit of investigation on the

While on holiday in France, we fell in love with a derelict mill and made the spontaneous decision to buy it. That was over 23 years ago, and we have lived, worked and continued to restore the mill in France ever since.
Lymphoma Action website quickly made me realise that lymphoma isn’t just one cancer; there are many different types.

My diagnosis was mantle cell lymphoma stage 3 with my lymph nodes and spleen affected. I now realise that at the age of 63 and a man, I am the classic profile of someone with this type of lymphoma.

I was referred to the haematology clinic in the regional capital in France. I knew I was going to be in for some chemotherapy and having read around it, believed I would have R-CHOP. However, my consultant asked if I would be interested in a clinical trial called LyMa 101. Initially I was worried about being a guinea pig, but he went through the strict protocol in detail.

For the trial, the rituximab element (the R in R-CHOP) would be replaced with obinutuzumab (Gazyva®). My chemotherapy was also changed from CHOP to DHAP. It was explained that if I joined the LyMa 101 trial it would include an autologous stem cell transplant, using my own stem cells. This would be followed by three years of immunotherapy using obinutuzumab.

Part of my reason for taking part in the trial was that I understand how important it is to get people involved in

More about mantle cell lymphoma (MCL)

Mantle cell lymphoma is usually a fast-growing type of lymphoma, but some cases grow slowly.

500 cases diagnosed each year in the UK

MCL accounts for around 5-7% cases of non-Hodgkin lymphoma

The median age of someone being diagnosed with MCL is 60-70

Mantle cell lymphoma is more common in men than women

It is a time of change for the treatment of MCL and there are a number of trials currently open for this type of lymphoma.

Note: Stephen was treated for mantle cell lymphoma in France.

Lymphoma Matters Summer 2018
I was pleased to get home. I had not been eating in hospital as everything tasted horrible, whereas when I got home I could graze on a little of what I fancied eating. This really helped me build up gradually. My hair had gone and I was surprised that my usually straight hair came back curly. And I seem to have more hair now too!

Throughout the whole process I never stopped working. As an estate agent I do a lot of work on the phone and by email, which I can do anywhere. The nurse felt that this was good for me psychologically as it gave me something to think about. I am a fairly fit person and used to run and cycle. Once I was out of hospital, I started walking, increasing the distance I went each day very slowly. Within two to three months of the stem cell transplant, I felt pretty much back to normal.

I have to go to the haematology unit for the immunotherapy, obinutuzumab, which is part of the clinical trial protocol. I have this every two months and will continue to have it for three years.

I had the usual side effects that I had been expecting, such as hair loss and fatigue, but the thing that I really noticed was how awful everything tasted. Just before the fourth chemotherapy cycle, they took me in to harvest my stem cells. I was given growth factors which increased my production of stem cells. I was connected to a machine while the cells were harvested, followed by the final chemotherapy. I had a break in treatment of about a month, and then I was taken into hospital for my autologous stem cell transplant. I had read about the process and thought I knew what I was in for. But nothing prepared me for how tough it was. I had most dreaded the idea of the isolation, but the BEAM chemotherapy was really awful. I went downhill really quickly and struggled mentally and physically. I had to keep telling myself that it would be OK, but I had never felt like this before in my life. It was a really difficult time. I was in hospital for three weeks. My immune system vanished and I was in isolation for around 10 days.
Thank you to all those who ran in the London Marathon for us. All our 35 runners completed the course, in spite of the very hot weather, and we cannot thank them enough for their support.

So far they have raised over £80,000 for us, a magnificent amount, which will go to help those affected by lymphoma. Many of the runners met up with us after the event and it was truly inspirational talking with them about the day.

If you feel inspired, why not join Team Lymphoma at one of our events, such as the Bournemouth Marathon, the Bristol Half Marathon or the Scottish Half Marathon? For further details contact Adele at fundraising@lymphoma-action.org.uk

650 people have taken part in the London Marathon for us since 1999 when we first had guaranteed places.

£1 million raised over the last 19 years by our amazing Marathon runners.

40,000 people took part in the 2018 London Marathon.

35 people ran on behalf of Lymphoma Action this year.

At 24.7 °C 2018 was the hottest London Marathon on record.

Find out more at www.lymphoma-action.org.uk/Get-Involved
£80,000 raised so far this year by our London Marathon runners – thank you.
How often should I expect to have a scan at a follow-up appointment?

There are a number of reasons to scan people at follow-up; if you are experiencing symptoms, if your doctor wants to carry out further tests after a physical examination or if your blood tests indicate that your lymphoma may be coming back.

But if you are symptom-free, feeling well and not receiving any active therapy, then there is little evidence that a scan will be of any benefit. Clinical trials have been carried out to investigate whether scans pick up relapse early, and the answer has been ‘no’. However, if the lymphoma is growing near your kidneys or in the brain, then you may have additional scans because you can become ill very quickly.

Remember, the patient will beat the scan to knowing when they are relapsing and so you should contact your medical team immediately if you have any concerns.

Chimeric Antigen Receptor (CAR) T-cell therapy is being carried out in the USA. Is this experimental or is it in common use in America?

There are two licensed CAR T-cell products in the USA, tisagenlecleucel and axicabtagene ciloleucel, one for use in lymphoma and one for leukaemia respectively. While they are approved, they are still very expensive, so are only available to those who have healthcare insurance that would cover them for this very expensive treatment. So in that sense, this treatment is not in common use in America. Trials in lymphoma are due to take place in the UK using commercially produced CAR T-cell products.
Question to Jane Gibson, who was appointed one of the first Lymphoma Action Clinical Nurse Specialists 13 years ago. Reflecting back, what has been the biggest change in the management of lymphoma during your career?

I actually started working within haematology, and specifically lymphoma, 20 years ago and during that time there have been significant changes in treatment. For example, the introduction of rituximab has improved the outcome of people with lymphoma. And the development of anti-sickness drugs mean that people are far better able to cope with the treatments given.

Another significant change is patient empowerment. In the past, you would visit your doctor and they would tell you the plan for treatment – and that was it. Today it feels like a patient healthcare partnership, where people are working with their medical team.

We carry out a lot of international trials in the UK. What do you think will be the impact of Brexit?

Clinical trials are carried out worldwide, with pharmaceutical companies based in places like the USA and Switzerland. It is the performance of the NHS in carrying out clinical trials that will make us attractive for research. However, there are elements that may have an impact, such as regulations between the EU and the UK. Hopefully, any effect of Brexit should be manageable.

I am part way through chemotherapy and my next treatment has had to be delayed because I have a low platelet count. Will this have an effect on my outcome?

It is difficult to answer specifically without all the details, but as a general rule chemotherapy is given on a three-week cycle because that is the average time it takes for your blood counts to recover. However, most cancer drugs have a lingering effect, so any impact is not that clear cut. Speak to your medical team about any concerns you have.

People of a certain age are entitled to have a shingles vaccination. Is there any reason why someone in remission should not have this?

The shingles vaccine is a live vaccine and is quite new. Certain lymphomas or certain chemotherapies might not be compatible with a live vaccine. As is often the case, you should take advice from your medical team.
As it’s summertime

As many of you will be going away on holiday it’s timely to cover planning a trip, travel insurance, vaccinations and sun safety.
Travel insurance

Having lymphoma means that you need to plan ahead to get the right insurance. Travel insurance is often more expensive for people who have a health condition. This is because insurance companies calculate the cost of your cover (the premium) by working out:

- the risk you will make a claim
- how likely you are to cancel your trip
- how likely you are to fall ill abroad
- the cost of any medical treatment you might need.

If you have lymphoma, it is important to have medical cover as part of your insurance. Insurers will ask medical screening questions which can be frustrating, but are needed to create a policy that is right for you. Don’t be tempted to hide anything or you might not be fully covered if you are unwell while you are travelling.

In countries where medical services are expensive, travel insurance can be costly. For example, USA, Canada, China, Hong Kong and the Caribbean have high medical costs. Some companies won’t insure you for these countries, but may do so if you’re going on a cruise. Australia, New Zealand and Europe have lower medical costs and some insurers class Egypt, Morocco and Turkey as part of Europe.

A company might offer you cover for medical conditions excluding your lymphoma. This is known as a policy with an exemption or exclusion. Although it is cheaper you may not be covered for any illness that your lymphoma might be linked to. For example if you develop a heart problem, the insurer might argue that there was a possible link between the chemotherapy you have had in the past and your heart problems now. If you are thinking about taking cover that excludes your lymphoma, ask your doctor for advice.

If you have an existing annual travel insurance policy, you must tell your insurer that you have been diagnosed with lymphoma.

They may agree to cover you for your lymphoma, although you will probably have to pay extra. If you don’t tell them, you are unlikely to be covered if you need to make a claim.
Taking care while away
Lymphoma affects your immune system and makes it harder for you to fight infections. This means you need to take extra care, especially while travelling. Here are just a few tips. You can read more at www.lymphoma-action.org.uk/Travel.

- Be sure that water is sterile before you drink it. The easiest way of doing this is to boil it. Many people think that bottled water is pure and free from bacteria, but it isn’t always the case.
- Avoid ice in your drinks, unless you know it is made from sterilised water.
- Avoid salads and unpeeled fruit, unless you are sure they have been washed thoroughly in sterilised water.
- Protect yourself from mosquito bites (which can cause infection) and mosquito-borne diseases.

Travel vaccinations and malaria
Your GP or travel clinic can advise you about whether you need travel vaccinations. Seek medical advice at least eight weeks before your trip, as some vaccinations have to be given well before you travel to be effective.

Some vaccinations are not recommended for people with lymphoma. Generally, these are ‘live’ vaccines (such as shingles, chickenpox and yellow fever). Live vaccines are made using bacteria or viruses that are weakened but still alive. The vaccines may be unsafe if you have lymphoma because they could cause a serious infection.

If you are unable to have a strongly recommended travel vaccination because of your lymphoma, think carefully about how necessary it is to make the trip. Weigh up the risks and speak to a member of your medical team or an advisor at a specialist travel clinic for advice.

If you have lymphoma, you should be particularly wary of travelling to areas where malaria is widespread.

Anti-malaria tablets can significantly lower your risk of getting malaria. Your GP or travel clinic can advise you on whether you need anti-malaria tablets and which ones are best for you. Their advice will depend on factors such as your age and medical history, as well as where you are going.

Acknowledgements
With thanks to Charlotte Bloodworth, Lymphoma Clinical Nurse Specialist at the University Hospital of Wales for reviewing this.
The American Society of Hematology (ASH) meeting in December is the largest gathering of lymphoma experts worldwide. In January, UK experts met in London to talk about the latest developments presented at ASH and their implications for clinical practice in the UK. Our Senior Medical Writer, Dr Becky Salisbury, was at that meeting, and provides an overview.

**Low-grade non-Hodgkin lymphoma**
New drugs and maintenance were key topics of discussion.

**Mantle cell lymphoma**
Maintenance treatment after successful first treatment keeps mantle cell lymphoma (MCL) under control for longer and extends life. Ibrutinib is now recommended on the NHS for people who have had one previous course of treatment. The benefits of ibrutinib are much greater when it is used early for people with MCL.

**Follicular lymphoma and maintenance.**
The PRIMA trial showed that maintenance kept follicular lymphoma under control for longer than active monitoring (watch and wait). Ten years on, around half of the people...
treated with maintenance in the PRIMA trial are still in remission compared with around a third of people who did not have maintenance, but questions remain.

Is there a benefit to maintenance when it is given after newer regimens (combinations of drugs)? How long should it be given for?

• The MAINTAIN trial showed that there is a benefit of maintenance after rituximab and bendamustine.
• There is no clear evidence that longer maintenance is beneficial: two years’ maintenance remains standard care.

Rituximab remains the most widely used treatment for maintenance in low-grade NHL, but is there anything better?

• The GALLIUM trial showed that the newer antibody obinutuzumab could improve outcomes further. However, there may be a greater risk of side effects with obinutuzumab.
• Adding a newer drug, lenalidomide, to rituximab maintenance didn’t have any benefit and caused more side effects than rituximab alone.

Maintenance increases the time people live without needing more treatment but doesn’t seem to increase the time people live overall.

• More research might identify people who won’t benefit from maintenance, so they can avoid any side effects.

**Chronic lymphocytic leukaemia (CLL)**

New treatments are still big news for CLL, and new guidelines for the management of CLL being developed by the British Society of Haematology will bring these into standard practice.

The CLARITY trial showed that the combination of two targeted drugs, ibrutinib and venetoclax, gives high response rates and can completely clear CLL in some people who have already received other treatments. Following on from this, the ongoing FLAIR trial is testing whether standard chemotherapy, ibrutinib alone, ibrutinib with rituximab, or ibrutinib with venetoclax gives the best outcomes for people with untreated CLL.

Venetoclax is an option if other targeted drugs have failed to keep CLL under control, but it could be used for earlier relapses in the future. The MURANO trial showed that more than twice as many people treated with venetoclax and rituximab (82.8%) were still in remission for two years after treatment, compared with standard treatment of bendamustine and rituximab (37.4%).

With new approaches improving outcomes for people with CLL, the biggest treatment challenge is Richter’s Syndrome. Richter’s happens when CLL transforms from growing slowly to growing quickly. It is challenging to treat and new approaches are urgently needed.

**A note on targeted drugs**

Targeted drugs are always of interest for improving treatment outcomes. However, trials have shown that caution should be used when adding these drugs to standard treatment. Many lymphoma treatments cause immune system cells to be destroyed, so adding other drugs that affect the immune system can increase serious side effects like infection. The results of these trials are important in guiding the next steps in testing how these drugs could be used safely.

**High-grade non-Hodgkin lymphoma**

High-grade (fast-growing) non-Hodgkin lymphoma (NHL) is particularly challenging to treat if it relapses, but approaches being tested have encouraging results.
CAR T-cells have now been big news for some time and are getting closer to becoming available for people with lymphoma. Find out more on page 8.

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

Newer drugs have been tested in DLBCL for some time with little success, but antibody-drug conjugates, such as polatuzumab vedotin and ADCT-402, are giving more promising results in clinical trials. These drugs conjugate or join a strong chemotherapy drug with an antibody that targets the lymphoma cells. The antibody takes the drug directly to the lymphoma cells, reducing the effects of the drug on healthy cells.

**Anaplastic large cell lymphoma (ALCL)**

Etoposide may be added to CHOP chemotherapy (CHOEP) for some people with ALK-positive anaplastic large cell lymphoma (ALCL) after a clinical trial showed that people with the ALK protein benefit greatly from the addition.

**Hodgkin lymphoma**

Treatment for Hodgkin lymphoma is generally very successful. Research continues to focus on improving the outcomes for people who don’t respond well to their first treatment and on reducing the side effects of treatment for people who do well.

Brentuximab vedotin is a newer drug that can now be used for some people with classical Hodgkin lymphoma who need more treatment. Many clinical trials are trying to find out if using it as part of first-line treatment can replace the more toxic drugs in standard treatment as well as increasing the number of people who respond to treatment. Most of these trials replace the bleomycin (B) in the standard ABVD chemotherapy regimen with brentuximab. Results from trials in both early and late-stage Hodgkin lymphoma suggest that this approach makes treatment slightly more effective but it also causes some serious side effects. There is still debate over the best time to use brentuximab for treatment of Hodgkin lymphoma.

Trials in early-stage Hodgkin lymphoma are also testing whether the amount of radiotherapy given can be reduced without reducing the effectiveness of treatment, with promising results.

Escalated BEACOPP is often considered as a treatment for people with advanced Hodgkin lymphoma who have a high international prognostic score, which means they have lots of factors that mean their lymphoma might be difficult to treat (risk factors). BEACOPP can be more effective than ABVD but also causes more side effects, with a greater risk of causing infertility. A new approach showed that people who respond well to the first two cycles of escalated BEACOPP do just as well if they have only two more cycles instead of the usual four or six more cycles, reducing side effects.

There are also increasing treatment options for people who relapse, including more chemotherapy and a stem cell transplant, brentuximab, and checkpoint inhibitors (drugs that harness the power of your immune system to fight the lymphoma). One study showed that checkpoint inhibitors could even still benefit people whose lymphoma is getting worse while they are on treatment as long as they feel well.

To read more news stories about clinical trials and to find a trial that might be suitable for you, visit [www.lymphoma-action.org.uk/TrialsLink](http://www.lymphoma-action.org.uk/TrialsLink)

**Acknowledgements**

With thanks to Dr Robert Marcus for reviewing this summary.
I noticed a swollen gland near my left collarbone around early Summer 2014. After a couple of weeks of it not going down, I made an appointment to see the doctor.

I was referred to the hospital to have an ultrasound scan on my neck, but at the time they said they weren’t concerned about it. They said if it persists I should go back to my doctor.

I knew this just wasn’t right. I am no expert, but I was pretty sure that glands are supposed to go down and mine hadn’t. In addition, I had lower back pain, tiredness, swollen glands and itchy skin. So I went back to the GP for a second opinion and was referred back to the hospital, this time for a fine needle biopsy.

Waiting for the results was difficult, but during that time I researched my symptoms and came across the Lymphoma Action website. I think I had already come to the conclusion it was a type of lymphoma by the time I had the diagnosis.

At the end of September 2014, I was diagnosed with Hodgkin lymphoma, stage 4B. Despite expecting a lymphoma diagnosis, I was still pretty shocked. After all, I considered myself healthy! My husband, who up until that time had been fairly laid back, suddenly realised that things were serious and was almost more shocked than I was.

I was 34 at the time and the only positive thing about this was that this is the most common cancer among the under 30s.

I was to start treatment straightaway with six months of ABVD chemotherapy. I was offered the option to take part in a clinical trial, but I would have had to travel some distance, so decided not to. The six months of chemotherapy
Nearly 2,000 people are diagnosed with Hodgkin lymphoma in the UK each year.

Did you know?

Find out more about Hodgkin lymphoma at www.lymphoma-action.org.uk/HL

PERSONAL EXPERIENCE

A scan part way through showed that everything was going well. My final dose of chemotherapy was on 15 April 2015 and I was given the best news. I was in remission.

I was thrilled to be back in good health. I had always wanted to do a skydive, but had never had any cause or reason to do one. I felt there was no better time to jump out of a plane than now and fundraise for Lymphoma Action. I did a tandem skydive, raising £2,000 for the charity that provided me with all the information I needed.

I had trained as a hairdresser and have always had an interest in hair and beauty. I wanted to use my experience of hair loss and the tips I picked up through my experience in an inspiring way. I have teamed up with an organisation, and work as an ambassador, plus I also work closely with people to help them choose a wig. Check out my site at www.promozo.com.

Zoe

Makeup and faux hair allowed me to still feel myself.

Would you like to take on a challenge like Zoe?
Go to www.lymphoma-action.org.uk/Challenge to find out more
Why watch and wait?
While it might seem counter-intuitive, with low-grade non-Hodgkin lymphoma, early diagnosis and treatment makes no difference to outcome, so watch and wait is often the best option.

Even if lymphoma is in a number of places (including the bone marrow), so long as you are feeling well and the disease is causing you no problems, then it is fine to leave it alone. Watch and wait, or better, ‘active monitoring’ or ‘active surveillance’, does not compromise your outcome. This conclusion is supported by the results of trials that have been performed in this country in which groups of people diagnosed with low-grade non-Hodgkin lymphoma, but who are generally well, have been split into two sets – one being treated and the other not.

After long-term follow-up, we have seen that there is no difference in how long the different sets of people live. Any treatment can expose people to side effects, but without proven benefits in outcome it is sensible to watch. Indeed people can be on active monitoring for many years.

I think that the challenge is in coping psychologically with the idea that you have been told that you have a cancer, but are not going to be treated. That seems wrong, but is, in fact, the right thing to do. It is important that your medical team explain this clearly to give you the reassurance that this is the most appropriate course of action and does not compromise you. Don’t hesitate to ask all the questions you want so that you are clear about this approach and your concerns are covered.

What happens when I am on watch and wait?
While on watch and wait you will attend clinics, although probably less and less often as time goes on. Don’t be concerned if you do not receive frequent scans. They will be performed if there is a change in your clinical situation, particularly if you become unwell, and treatment options will be discussed at that point. Remember that you will not become unwell overnight – it is a gradual process.

While your clinical team will not need to see you very often, they will want you to keep an eye on yourself. You are the best person...
to know how you are feeling, and you should tell a member of your medical team if you feel unwell. If things do not change over a reasonable period of time, then the time between visits to the clinic will probably be extended.

What should I look out for?
You need to be aware of particular things like night sweats, fevers and weight loss. However, remember, if you come down with flu, then you may experience these symptoms without it indicating a change in your lymphoma.

Symptoms of low-grade non-Hodgkin lymphoma come on gradually – you are not going to be fine one day and then really ill the next. On the other hand, if you develop these symptoms gradually, particularly unexplained weight loss, lumps, or just don’t feel quite right for no apparent reason, then you should inform your medical team.

What should I do if I’m worried between appointments?
If you are worried between appointments, either see your own doctor or, if you have a phone number for your clinical nurse specialist, talk it over with them; they may suggest you come in. Your doctor would rather see you than wait for six months when you might then be really quite unwell.

Talk about symptoms that are worrying you. If you are an older patient you may have other medical conditions that could be causing you symptoms but that have nothing to do with your lymphoma. Talking it over with your medical team may put your mind at rest.

Sometimes your GP might not be aware that you are under watch and wait for lymphoma. If so, you should talk to them, and ensure that they are aware of what to look out for during your visits. If in doubt, talk to your medical team.

Be aware of the most common symptoms of lymphoma:

- **Swollen lymph node**
  These are usually painless and are often noticed in the neck, armpit or groin. Not all lymphomas have obvious lumps.

- **Fatigue**
  This is not a normal feeling of being tired. It means you are exhausted for no obvious reason.

- **Unexplained weight loss**
  Losing weight quite quickly without dieting.

- **Sweats**
  Lymphoma can cause drenching night sweats. These can also occur during the day.

- **Itching**
  Itching without a rash can be a symptom of lymphoma.

Acknowledgements
With thanks to Professor Simon Rule, Consultant Haematologist at the Derriford Hospital in Plymouth.

Lymphoma Matters Summer 2018 | 27
Not the same experience

The doctor called me in to give me the result of my biopsy, 'It's lymphoma, a type of cancer.'

I knew about cancer of course. But I had never heard of lymphoma. When he gave me the news I didn't feel panic, I didn't feel afraid and strangely I didn't feel ill.

What I did feel was fury. Anger. And a rising acceptance that this was the battle of my life. But also a determination that I was going to win it.

I had worked for forty years as a journalist in Fleet Street, and my wife Anna and I had retired and bought a small village house in the Alicante region of Spain to enjoy the sun.

In 2007, I had noticed a line of lumps to the left side of my groin. After a while they disappeared. But a few months later another lot of lumps appeared on the right side of my groin. We were in England, so I went to see my GP who sent me for a biopsy. That was when I was diagnosed with diffuse large B-cell lymphoma (DLBCL). We didn't get back to Spain for another seven months.

I was to have six sessions of R-CHOP chemotherapy. I sat in the day ward for most of the day while the drugs were given intravenously. I was assigned a specialist nurse and given telephone numbers; I was told I must call at any time if I had any serious concerns.

I waited for the unpleasant side effects. My hair started to fall out in clumps, which irritated me, so I took some scissors and cut off the lot.

Chemotherapy sessions were due to take place every three weeks. But before the second one I was asked if I would like to take part in a study called R-CHOP 14. The number 14 meant that instead of a session every three weeks, I would switch to every two weeks to study how different people responded to the more intensive treatment.

Six months after my last chemotherapy, and at the age of 84, I went off on a cruise with my wife Anna.
Very rarely, people diagnosed with a high-grade lymphoma, such as DLBCL, can relapse in the future with a low-grade lymphoma. It is not certain why this happens but tiny, undetectable levels of low-grade lymphoma may have been present at the initial diagnosis, which later caused a relapse.

Did you know?

Very rarely, people diagnosed with a high-grade lymphoma, such as DLBCL, can relapse in the future with a low-grade lymphoma. It is not certain why this happens but tiny, undetectable levels of low-grade lymphoma may have been present at the initial diagnosis, which later caused a relapse.

I was pleased to be chosen because that would mean I could get the entire thing over more quickly.

And then things really started to get rough. Something happened to my feet. It felt as though I was walking on razor blades. It was agonising. On my next visit to the hospital I had to be pushed around in a wheelchair. Eventually I got my feet back.

I had six cycles of chemotherapy. Soon after my treatment ended I received a letter telling me that the R-CHOP 14 study had shown there had been no difference in the response of people like me who took part and patients who had remained on the three week sessions. Although a little disappointing, I was glad to have been able to do my bit. Over the next five years things seemed to be going well. My specialist suggested I be discharged and I couldn’t have been more happy.

Early in 2016, the shingles virus attacked my left eye and the rash manifested itself on the left side of my face. I have never known pain like it. I began to get other mysterious infections. One night I was on my way to the bathroom when I fell and couldn’t get up. My legs simply wouldn’t support me. It turned out I had pneumonia and, while I was being treated in hospital, tests that included more CT and PET-CT scans were carried out.

The lymphoma was back. In March 2016 the lymphoma returned in the form of a low-grade version.

So it was a return to the clinic. I needed to start chemotherapy again. There was rituximab one day, which took all day hooked up to a drip. The following day was for bendamustine, which took only one hour. This was done every month.

I expected everything to happen as it had done before on the chemotherapy regime: that my hair would fall out, that my feet would be attacked, that I would feel generally dreadful. But I didn’t.

Instead, my hair was just thinner and I didn’t feel ill. However, my tongue and teeth turned black and I had the more painful mouth sores. I was treated immediately with mouth washes, ointments and tablets. My oncologist stopped the bendamustine treatment because it was causing too many problems for me.

It has now been six months since my last chemotherapy and two things have happened. First, I have been able to get travel insurance, secondly the oncologist doesn’t want to see me again for four months. So, at the age of 84, I went off on a cruise with my wife Anna.’

John
One of the most important things you need to know if you have a diagnosis of cancer is that we are all protected by something called the Equality Act 2010. This Act protects people who have had cancer from discrimination in employment from the point of diagnosis for the rest of their lives. It doesn’t just cover the period you are ill or having treatment, but it is forever. This means you are protected in terms of recruitment, training, promotion, terms of employment, how you are paid, appraised, how you leave work and even your references. There is plenty of information on the web that will help you to understand your rights.

When you need to speak to your employer depends on the nature of your diagnosis, your relationship with the company and your manager, the type of work you do and the size of the company. But it is possible to identify four key stages where a discussion is necessary or desirable.
The first time to talk to your employer is as soon as you have had your diagnosis. Sit down with your boss and HR and talk about the implications of your diagnosis and explain what support you need at this stage. You may need lots of information, for example about pay, sick leave or health cover.

Consider how much you want your colleagues to know and agree with your company what you want said about your situation.

The second time you need a conversation is when you will be away having treatment. This is the time to talk about cover arrangements, what is said at work about your absence and agree how you want to keep in touch.

The third time you need to talk is a few weeks before you are due to go back to work, after treatment has finished. You should be talking about making a phased return to work, reasonable adjustments, any cover arrangements needed, and the hours you will be working. In addition, you should discuss what you want said about your return to work and how you feel about talking about your cancer to colleagues.

Back at work
The fourth time to speak to your employer is once you are back at work. It is important to have a conversation with your manager and HR to discuss how adjustments are working out. You may want to speed up your phased return, or you may need to slow things down. There may be elements of your return that are not working that you need to discuss.

A regular meeting with your manager, HR, or both together, is important for about 12 months or longer. Prepare for these conversations and plan beforehand what you are going to say or ask.

Write down your questions in advance and take notes in these meetings. Afterwards try to write an email or letter setting out your understanding of what has been agreed. Then everyone will be clear about the situation.

Top tips
1. Understand your rights
There is plenty of information on the web.

2. Be open and honest with your employer
Talk about your diagnosis and potential treatment as soon as you are aware you are going to have treatment, then you can get the support and protection you need.

3. Expect the unexpected
You might have certain expectations of how you will be, but things rarely work out as you think. Ensure that your employer appreciates this.

4. Try not to commit too much
In the early stages you do not know how you are going to feel physically or mentally, so try not to commit to doing things, as you may not be well enough to do what you promise.

5. Over communicate
Talk about your cancer as much as you feel you want to so that people know how you are and understand the situation.

If you would like to contact Working With Cancer for information or support, or would like to find out more about their services visit www.workingwithcancer.co.uk or send an email to admin@workingwithcancer.co.uk.
Lymphoma Action
Support Groups

Aylesbury
Bangor
Bath
Bolton
Cambridge
Canterbury
Cardiff
Cheltenham
Colchester
Colne
Coventry
Driffield
Frodsham
Glasgow
Guildford
Ipswich
Isle of Man
Kendal
Lancaster
Leeds
Leicester
Macclesfield
Manchester
Milton Keynes
Mold
Nantwich
North Mersey & West Lancs
North London
North West Middlesex
Norwich
Oxford
Peterborough
Plymouth
Poole
Portsmouth
Preston and District
Reading
St Helens
South East London
South West Essex
Southampton
Stevenage
Swansea
Swindon
Tayside (Dundee)
Teesside
Truro
West Midlands (Sutton Coldfield)
Whitehaven
Wigan
Wirral

Lymphoma Action Support (closed Facebook support groups): North West, South West, Yorkshire & North East

For more information about any of our groups, or details of independent groups, please call us on 0808 808 5555 or 01296 619400. You can also email information@lymphoma-action.org.uk or visit our website at should be www.lymphoma-action.org.uk/SupportGroups.

Expanding our reach

Our first two Regional Development Managers (North West and South East) were recruited in 2014 for a pilot project to increase our regional support services. As a result, we have seen increased engagement with people affected by lymphoma, health professionals and independent cancer networks in these regions.

This tells us that an ‘on the ground’ regional approach works and that expanding our regional presence will help people affected by lymphoma across the UK to access the full range of support they need.

With the support of a grant from the Roger Counter Foundation, we have now expanded our regional development programme and will report on this exciting development over the next few issues.

New group in Whitehaven

A new group has launched in Whitehaven, Cumbria in May. The group meets at the Bransty British Legion, Whitehaven. For further information contact Karen on 07710 393891.

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

Web: www.lymphoma-action.org.uk
Phone: 0808 808 5555
Email: information@lymphoma-action.org.uk
Facebook: @LymphomaAction
Twitter: @LymphomaAction
Instagram: @Lymphoma_Action
We simply couldn’t reach all the people we do without the support of our amazing volunteers

We are delighted to welcome Carly Benton as our first Volunteering Development Manager. Carly’s interest in volunteering sparked from being a volunteer herself, helping young carers, which is something she continues to do. After graduating, Carly wanted to use this experience in her career. She has worked at the University of Hertfordshire and Crohn’s and Colitis UK, in both cases supporting volunteers and managing a volunteering programme.

Carly explains: ‘Volunteers are enormously valued at Lymphoma Action. I am looking forward to working with staff and volunteers to develop volunteering at the charity. In addition, I know the charity are expanding opportunities for volunteers and I am looking forward to putting a programme together to recruit, train and recognise new volunteers, as well as developing the relationship with those already involved with the charity.’

Our volunteers give their time and energy to help others affected by lymphoma. Their skills and involvement in the charity are really diverse. Here are a few of the things our wonderful volunteers do:

- Support groups are run by volunteer coordinators
- Buddies are specially trained to offer peer support
- Trustees govern the work we do
- Ambassadors help us raise awareness of lymphoma and represent us in their local area
- Advisory panel members shape and inform our work
- Medical advisors keep us up-to-date with medical information and advances
- Reader panel members ensure our information is accessible and comprehensive
- Live your Life coordinators facilitate workshops for people living with and beyond lymphoma
- Fundraising groups ensure we can continue with the work we do to support people by organising local fundraising activities. They run, cycle, bake cakes, hold quiz nights, (too many things to mention in this small space).

Take action with us to help inform, support and connect people by registering your interest in volunteering on our website www.lymphoma-action.org.uk/Volunteering or contact us by email at volunteering@lymphoma-action.org.uk

New role for Volunteering Manager
DO WHAT YOU LOVE for lymphoma

Could your passion, hobby or talent help to raise money for people affected by lymphoma?

Getting a small gathering together, suggesting a small donation and sharing what you love to do could really make the difference that someone with lymphoma needs. We rely almost entirely on donations to fund our information and support services, so why not take action and Do What You Love?

You could get friends and family together and pamper them by painting their nails. Alternatively you could hold a story-telling evening and read your favourite book to an audience. Why not hold a games night or share a skill? It could be anything – cooking, DIY or yoga – for a small donation.

It doesn’t have to be big or exhausting. Do What You Love - your small actions can have a huge impact on people with lymphoma.

Would you like to do something to raise money for people affected by lymphoma but you’re not sure what you could do? It is time to set your imagination free and Do What You Love!

www.lymphoma-action.org.uk/dowhatyoulove
#LymphomaAware #LymphomaMatters #DoWhatYouLove
Thanks to a Big Lottery Fund, we are able to offer our Live Your Life workshops free of charge. They are designed for people who have recently finished treatment or are on active monitoring, and cover:

- what lymphoma is
- coping with the emotional aspects
- getting active after diagnosis and treatment
- maintaining a healthy lifestyle.

They also offer a great opportunity to meet others affected by lymphoma and share experiences.

Join us at one of our Live your Life events being run throughout the UK:

- **Harrogate**  Monday 2 July 2018
- **Boston**  Tuesday 3 July 2018
- **Cardiff**  Friday 6 July 2018
- **Wolverhampton**  Wednesday 11 July 2018
- **Newcastle**  Thursday 19 July 2018
- **Blackburn**  Wednesday 12 September 2018
- **Frimley**  Thursday 20 September 2018
- **Liverpool**  Thursday 27 September 2018
- **Bath**  Friday 28 September 2018
- **Exeter**  Thursday 4 October 2018
- **Portsmouth**  Thursday 4 October 2018
- **Poole**  Wednesday 10 October 2018
- **Oxford**  Wednesday 10 October 2018
- **Peterborough**  Friday 19 October 2018

To find out more about our upcoming events, visit our website [www.lymphoma-action.org.uk/LYL](http://www.lymphoma-action.org.uk/LYL)
Peripheral T cell lymphoma not otherwise specified (PTCL-NOS)

T-cell lymphoma

Chronic lymphocytic leukaemia/small lymphocytic lymphoma

non Hodgkin lymphoma

Diffuse large B-cell lymphoma

intravascular large B-cell lymphoma

Primary mediastinal large B-cell lymphoma (PMBL)

Burkitt lymphoma

Mantle cell lymphoma

Primary central nervous system (CNS) lymphoma

Hodgkin lymphoma

Nodular lymphocyte-predominant Hodgkin lymphoma

Low-grade (slow-growing) B-cell non-Hodgkin lymphoma

Post-transplant lymphoproliferative disorder (PTLD)

T-cell skin lymphoma, eg mycosis fungoides

Follicular lymphoma

Lymphoplasmacytic lymphoma (Waldenström's macroglobulinaemia)

Learn more about clinical trials and the latest lymphoma treatment innovations.

Find out more and book your place:

lymphoma-action.org.uk/events

conferences@lymphoma-action.org.uk