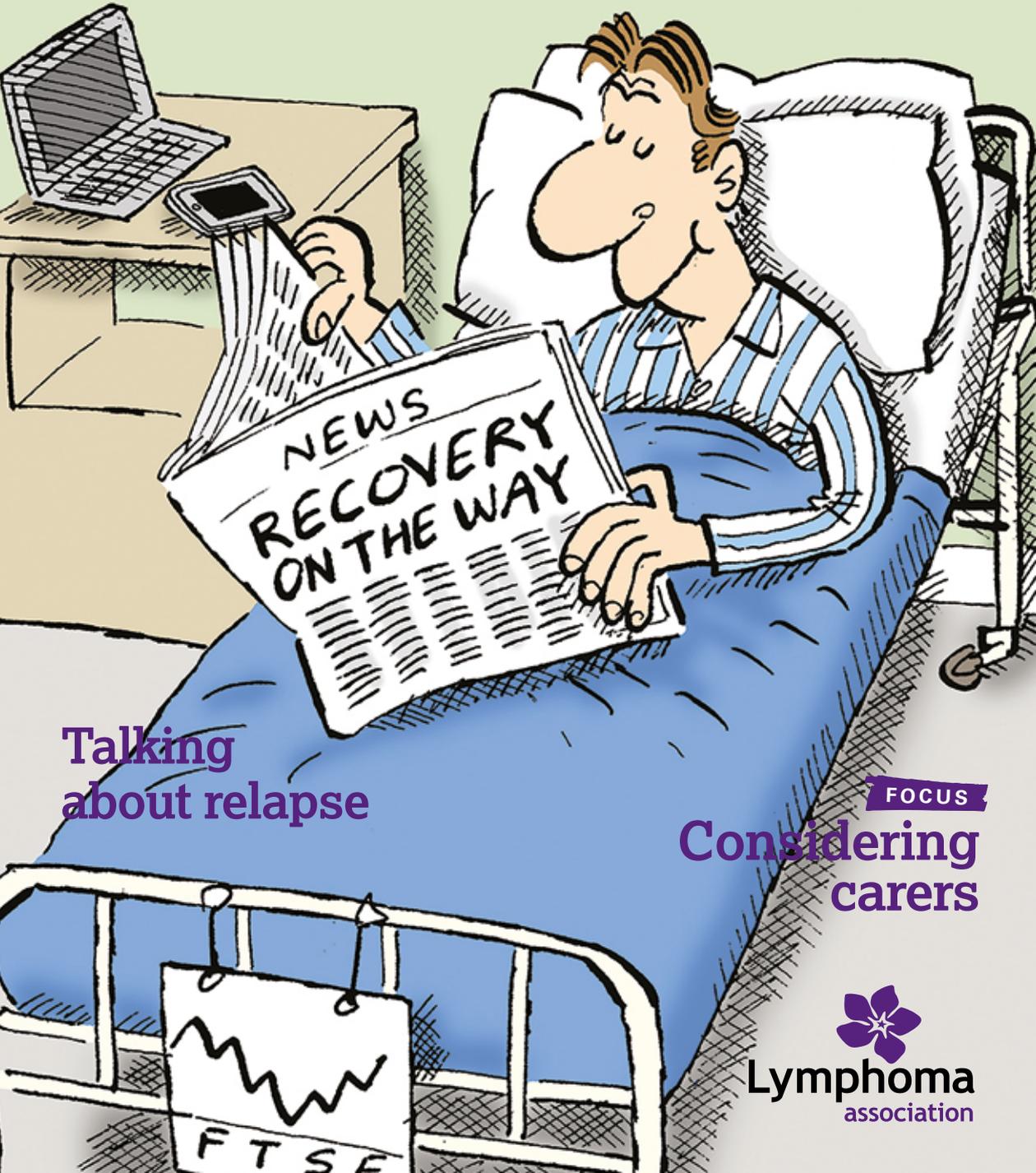


lymphoma

MATTERS

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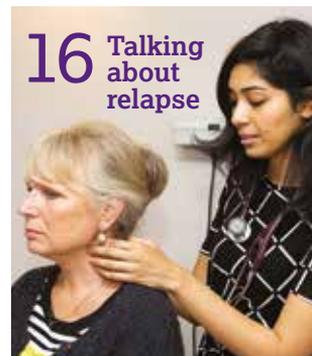
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The Lymphoma Association is a specialist UK charity that provides medical information and support to people with lymphatic cancer, their families and friends. Each year in the UK more than 19,000 people are diagnosed with lymphoma (including CLL), making it the fifth most common cancer diagnosed overall and the most common cancer in teenagers and young adults.

Views expressed in *Lymphoma matters* are those of the contributors. The Lymphoma Association does not necessarily agree with or endorse their comments.

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Cover cartoon: Charles Peattie
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Read the latest news on our Lymphoma Matters blog – www.lymphomas.org.uk/LMblog



Jonathan Pearce
Chief Executive

[@JPearceCEO](https://twitter.com/JPearceCEO)

To view the report, or provide feedback, contact communications@lymphomas.org.uk



Our thanks to Charles Peattie for producing the front cover. Charles and Russell Taylor, create the long-running cartoon strip Alex that appears in the Daily Telegraph. Read Russell's story on page 6.

3,380 people share their experience of lymphoma

Good things come to those who wait, or so they say. As you'll see on the following page, we're pleased and proud to announce the launch of a major survey and research report. Entitled *Understanding lymphoma as a cancer*, the survey polled lymphoma patients' on their experience of diagnosis, treatment and aftercare. The work on this report, including the design and testing of a detailed survey with our project partners, Quality Health, has taken 18 months, not least due to the numbers of people involved and the corresponding data analysis required.

With a response rate of about 80% and nearly 3,400 completed surveys, the data and report amount to a significant, credible and valuable dataset on patient experiences of lymphoma, including their access to much-needed information and support – and it's clear much, much more can be done.

Perhaps most notable from the survey's findings is how little people are told about their lymphoma subtype. 14% of people were told simply they had lymphoma – no more, no less. Only 13% of the respondents were told they had a subtype of non-Hodgkin lymphoma (NHL), when the figure should have been more like 85%.

Similarly, the data on access to clinical trials showed a missed opportunity. Only 23% of people were told about or offered access to a trial. Yet for those offered the opportunity, about two-thirds (66%) went on to join a trial, in most cases giving them the chance to access a new and/or innovative treatment. This reinforces the need for services such as our Lymphoma TrialsLink, which can be accessed via our website.

There's a lot more in this important research report, including the recommendations we've made as a result, and we would welcome your feedback.



Findings of lymphoma report to be displayed at Public Health England event

An extract of our upcoming *Understanding lymphoma as a cancer* report is to be presented at the 2017 Public Health England/National Cancer Registration and Analysis Service's 'Cancer Data and Outcomes Conference' in Manchester mid-June.

Last year, in partnership with Quality Health, we surveyed close to 4,000 lymphoma patients currently in treatment in England. We wanted to find out more about their experiences of being diagnosed and treated for lymphoma, and about their access to information, support and aftercare.

An extract of this survey was selected by a judging panel from Public Health England

and we have now been invited to present a collection of the report's findings in poster format at the conference.

Erika Murigi, our PR and public affairs manager, said: 'The results from this survey have provided a powerful dataset – the largest of its kind on lymphoma patient experience.

'It has been incredibly insightful to learn more about the experiences of

lymphoma patients and from this report we have developed 10 recommendations that we believe, if implemented, would significantly improve how people affected by lymphoma are diagnosed, treated and supported.'

The *Understanding lymphoma as a cancer* report will be available to download from our website in the coming months. To view a copy before then, please contact communications@lymphomas.org.uk

Hodgkin lymphoma treatment gets green light

Adult Hodgkin lymphoma (HL) patients in England, Wales and Northern Ireland who relapse following an autologous stem cell transplant will now have routine access on the NHS to brentuximab vedotin (Adcetris).

The National Institute for Health and Care Excellence (NICE) reversed its initial proposed recommendation and approved the use of brentuximab vedotin for this patient population, which was one of three indications for which the drug was appraised.

Brentuximab will also be available via the Cancer Drugs Fund (CDF) for HL patients unable to have a stem cell transplant, for example, because they still have active disease. The support of the CDF will enable more clinical data to be collected. NICE will review the drug again in two years for this indication.

NICE has not recommended the treatment for patients that are at high risk of their disease returning after an autologous stem cell transplant.

Jonathan Pearce, our chief executive, said: 'This will be a great relief to many HL patients and their families who would otherwise face limited or no treatment options.

'Given the potential impact brentuximab can have on patient outcomes and long-term survival, it has been frustrating how long it has taken for a recommendation to be agreed between NICE and the manufacturing company. Unfortunately, the frustration will continue for some patients and their loved ones while the treatment for use in pre stem cell transplant patients is further assessed through the CDF. We can only hope that all those involved will work together to expedite the final decision on access to brentuximab for other indications.'



ICT to get a boost, including a new website

This spring we launched an information and communication technology (ICT) development programme, thanks to some significant legacy donations (see page 24). The programme will improve the information, support and other services we offer by modernising our ICT systems.

Approved by our Board of Trustees in April, the first tranche of the programme will run for the rest of this year, improving the security and robustness of the IT used, and setting the foundations for future improvements.

The most noticeable change will be a new website, which is planned to be launched at the end of the year. The new website will be easier to use and will enable us to launch new services and information more easily in the future.'

Stephen Scowcroft, our head of business development, said: 'This is a really exciting piece of work for us. It will deliver a real improvement in the quality of both the online and offline services we provide to our supporters, healthcare professionals and those affected by lymphoma.'

“In November 2015 I bought my first house. I was 55 and I’d put it off for years because I’d been waiting for the supposed London property market crash, which just about everyone, apart from estate agents, had been predicting. Having finally taken the plunge, I looked proudly round my proper grown-up home and said (maybe to myself, maybe out loud): “This is the house I will die in”. Three months later I was diagnosed with cancer.

Tempting fate

Now obviously when I talked about dying I hadn’t anticipated it happening on any immediate timescale; I had planned on living through several more happy decades, enjoying a few productive middle years, possibly retiring at some point (or, as I’m self-employed, maybe just cutting down a bit on my workload), dandling grandchildren on my knee one day, pottering around in the garden - all that sort of standard stuff. But now here it was. Death had muscled its way to the front of the queue ahead of those other more pleasurable and civilised activities.

As well as being scary and slightly surreal, my diagnosis of non-Hodgkin lymphoma

seemed to be profoundly unfair. I’m a vegetarian. I’ve never smoked or taken drugs. I drink in moderation. I cycle and run regularly. My parents are both alive in their 80s. All the factors indicate that I should be in a very low risk category. Yet it seemed I had wasted a load of time getting up early and going to the gym, that my carnivorous couch potato contemporaries had spent more enjoyably drinking in bars or having a lie-in. And I was the one who’d ended up with cancer.

I didn’t even have any symptoms. My diagnosis came up in a routine blood test for something else. It was a sort of existential illness: I only had my haematologist’s

word for it that I was ill at all. I had to trust him; and, worse still, I had to trust him when he told me that I’d need to have chemotherapy. He’s very persuasive, so I signed up to do six months of chemo starting in July last year. That way, I reasoned, I could get it all out of the way by Christmas.

The drug I was treated with was bendamustine, which is a derivative of mustard gas. So ironically on the 100th anniversary of the Battle of the Somme I found myself in a chemotherapy ward in a North London hospital having this notorious poison drip-fed into my veins. It’s good to know that life has a sense of humour. And at least, like World War One, this grim experience would hopefully be over by Christmas.

I decided not to tell most people that I had cancer – more for their sake than mine. People don’t know what to say. Unfortunately the question “how are you?” is the prelude to just about every social interaction: when people meet you, when they call you on the phone, in emails. Even strangers greet you with it. What do you say in reply? Do you tell them you’ve got cancer straight up? Or just say breezily that you’re fine and feel you’re living a terrible lie?

The six months passed surprisingly quickly. I had

a PET scan in January and was told the cancer had totally gone: 100% remission. Unfortunately, the problem with non-Hodgkin lymphoma is that, like a villain in a Hollywood movie of the 1980s, it tends to come back. So my priority was now to keep it at bay as long as possible. As my haematologist reminded me, there are all sorts of amazing new treatments currently in development, so the longer I can stay healthy the better the drugs that will be available when the cancer returns.

Are there any positives one can take out of having cancer? Well actually there are. You get your problems into perspective

Most of what we think of as problems are of a financial or emotional nature: bills, mortgages, kids, relationships. While I was doing my chemo the whole world was stressing about Brexit and Trump. But what's the issue? Life will go on after both of them. And life going on is what it's all about.

These days of course our lives go on much longer than they used to, thanks to all the advances in medicine and science. But all that does is give us an excuse to put things off. I'm going to live to be 120 after all. Cancer

gives you that all important deadline. So when exactly are you going to do those things to change the world or your life? Write that novel? Start that business? Shall we get a date in the diary?

And despite it being a horrible random experience, there are ways in which cancer has restored my faith in life. As I mentioned earlier, bendamustine is a derivative of mustard gas. Now, mustard

gas has got to be up there in the list of the top ten most evil things ever devised by human beings. But the fact that I'm still around today proves that it can also be put to a positive use. Something that was devised to destroy life can be adapted to preserve it. Good can come out of evil. That's a nice positive thought to make me want to hang around in this world a good while longer.'

Russell



Russell Taylor MBE is half of the creative team that produces the long-running cartoon strip *Alex* in the Daily Telegraph. He is also a composer of TV music and has written books on Russia and marathon running. You can follow *Alex's* adventures at www.alexcartoon.com



ask the experts

Conference questions

This year's National Conference offered fascinating talks, including an overview of lymphoma, scans, late effects, latest developments and personal experiences. There was also the chance to try Nordic walking and mindfulness. As one delegate commented:

'The speakers and presentations were informative and impressive. I came away from the Lymphoma Association event having learned something new and understanding more about non-Hodgkin lymphoma, chemotherapy, and the side effects that have affected me.'

Save the date

We're already planning next year's National Conference and hope to see you in Manchester on Saturday 12 May 2018.



Here are some of the questions raised at the conference:

The 2017 conference talks were recorded and we have permission to share the majority of them via our website and YouTube channel. DVDs can be made available on request for a suggested donation of £5 to cover the cost of production, postage and packaging. Place your order by emailing conferences@lymphomas.org.uk

We've heard a lot about multidisciplinary team (MDT) meetings today. To what extent is the patient's perspective understood at these meetings?

One of the most critical things with lymphoma is to ensure an accurate diagnosis is made. What is reassuring about MDT meetings is that they bring together the experience of many medical professionals from various disciplines, including haematologists, clinical oncologists, pathologists, radiologists, clinical nurse specialists, occupational therapists and other members of the health team, to discuss test results and scans as well as treatment options. This allows you to feel confident that several opinions will have been sought before your lymphoma is diagnosed and the best treatment is recommended based on local and national guidelines and considering your personal circumstances.

Unfortunately, patients are not involved in the MDT meetings. By the nature of the meetings, various cases are discussed and may be referred to. Therefore there would be a problem of confidentiality. However if you want to have any wishes or concerns voiced at an MDT meeting, your clinical nurse specialist is probably the best person

to represent your views, so speak to them if you want to have anything included in the discussion.

Both my husband and his father have had a haematological disease; one with chronic lymphocytic leukaemia (CLL) and the other with myeloma. With two young children I am concerned whether there is a genetic link. Is there any screening for lymphoma?

It is understandable that family members are concerned about a potential link. For close relatives (father, brother, sister) the risk of developing lymphoma is slightly higher. Lymphomas are not common though, so the overall chances are still low. Unlike some cancers, there are no specific faulty genes for lymphoma that are inherited, ie passed on from parent to child.

Doctors would not routinely test for lymphoma based on family history, but it is worth having a heightened awareness of the symptoms.

I can't get my stamina back after treatment. Do you have any suggestions on what might help?

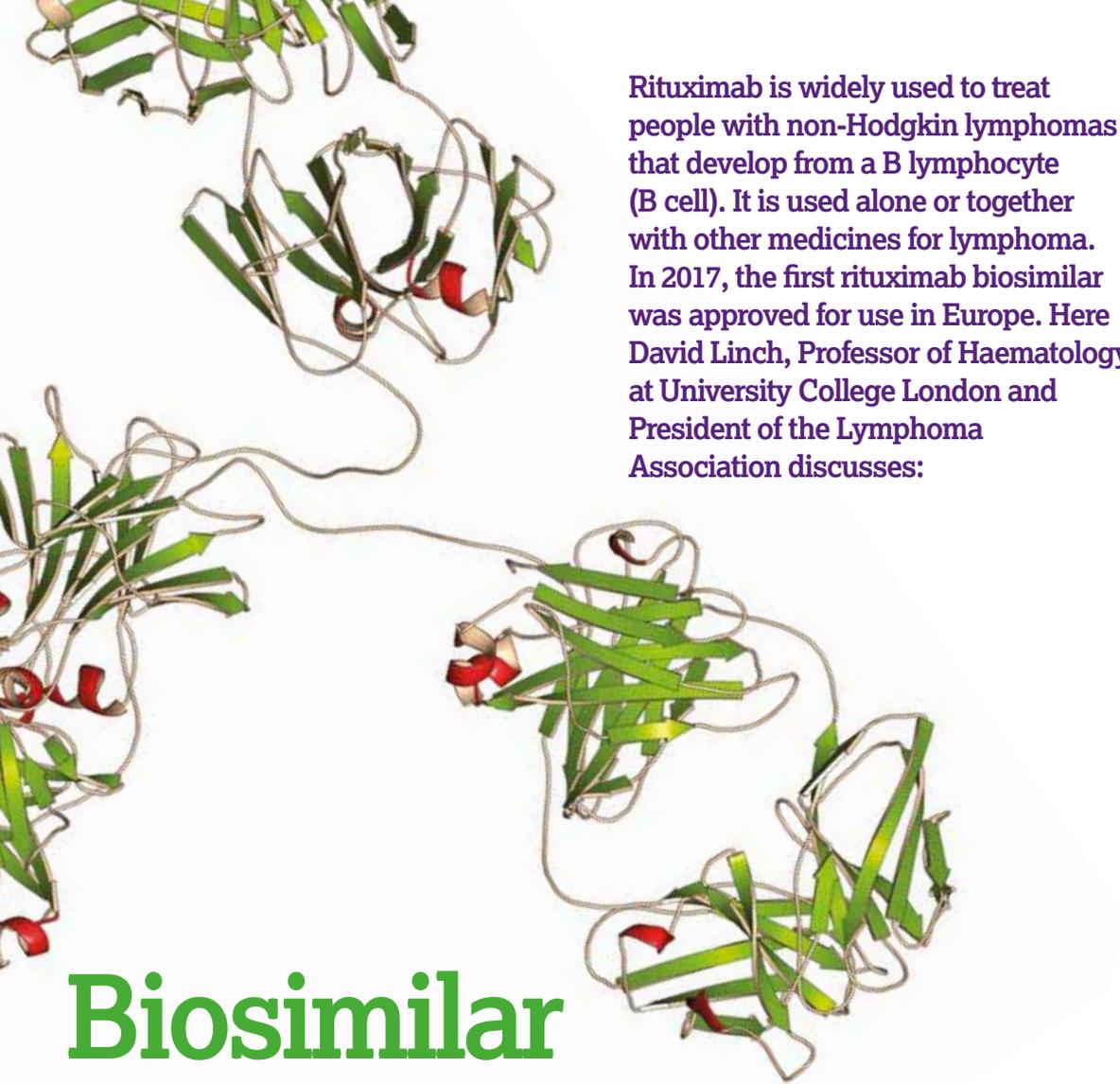
Often people try to push themselves too early and too soon. When people are finishing treatment there is an expectation of recovery

and an assumption that they will get back to the same condition as before their diagnosis. Of course, a lot depends on their fitness before lymphoma, their age and so on. As a result, they are often desperate to get back to normality and don't allow enough time to deal with the enormous amount their body has gone through.

It is important to try to set a reasonable level of expectation on recovery, allowing yourself time, particularly if you have had intensive treatment. Talk to those around you about how you are struggling with fatigue and also to your medical team, who may be able to offer some suggestions on strategies for coping.

If you are struggling because you have a lot of things you need to do at home or at work, try to avoid putting too much on yourself in the early days after treatment. It may be difficult to ask for help, but talk to the people around you and see if they can help you with some of these demands.

With thanks to Dr Cathy Burton, Consultant Haematologist at Leeds Teaching Hospitals, and members of our panel of experts for answering these, and other questions.



Rituximab is widely used to treat people with non-Hodgkin lymphomas that develop from a B lymphocyte (B cell). It is used alone or together with other medicines for lymphoma. In 2017, the first rituximab biosimilar was approved for use in Europe. Here David Linch, Professor of Haematology at University College London and President of the Lymphoma Association discusses:

Biosimilar rituximab is here: what does it mean?

Drugs can be broadly categorised into two groups, small molecules and biological agents.

Small molecule drugs, such as ibuprofen for example, are made chemically, whereas biologicals are larger, more complex

molecules that are produced by cells.

When any new drug is invented a patent is granted to the inventor or inventing company, which grants them exclusive rights so other companies cannot copy the

drug. In most countries, including the US and the European Union, this is for 20 years from the time of filing the patent application. However, drug development can take many years from the time of filing the patent application to the drug being

marketed and sold. This means that the effective patent life can be considerably less than 20 years and sometimes less than 10 years.

The purpose of patents is to encourage innovation, and during the period of exclusive rights, companies attempt to recoup their research and development (R & D) costs. Currently the average R & D cost for a new drug is estimated to be £2.2 billion, when the cost of drugs which fail in the testing phase (clinical trials) is taken into account. This explains, at least in part, the high cost of new drugs, and why a lengthy patent life is required to enable companies to recover their costs and so continue with novel research.

When a patent expires, other companies can start to manufacture and market this drug, subject to stringent quality assessment by the regulatory authorities. At this stage, as the R & D costs for the 'copy-cat' drug are relatively small, the price tends to fall dramatically, so releasing funds for other treatments.

In the case of small molecules, the drugs produced by the other companies are referred to as generic drugs. The generic drug can and must be 'virtually identical' to the original drug with regard to its structure, strength, the intended use, its effects, side effects and how it is given.

In the case of biological drugs, drug companies produce highly similar drugs known as biosimilars.

Requirements for the approval of a biosimilar may appear to be slightly less stringent in that it must be shown to be 'highly similar' to the approved reference biological product, with no clinically meaningful differences, but not 'virtually identical'. This is because the exact composition of a biosimilar is dependent on the cell line used to produce it, and the precise growing conditions employed, which can change over time (batch to batch variation, but within defined and approved limits).

Owners of the originator patent for the original drug are not obliged to provide the details of their manufacturing process, so some changes in production of biosimilars from the original drug are inevitable. The difference in

Terms explained

Small molecule drugs

Made by chemical process. Ibuprofen is an example.

Generic drugs

Exact copies of small molecule drugs.

Biological agents

More complex molecules produced by cells. Rituximab is a biological agent.

Biosimilars

A drug that is highly similar. As a natural product, there may be slight variations, but the drug has to be shown to be equally effective.

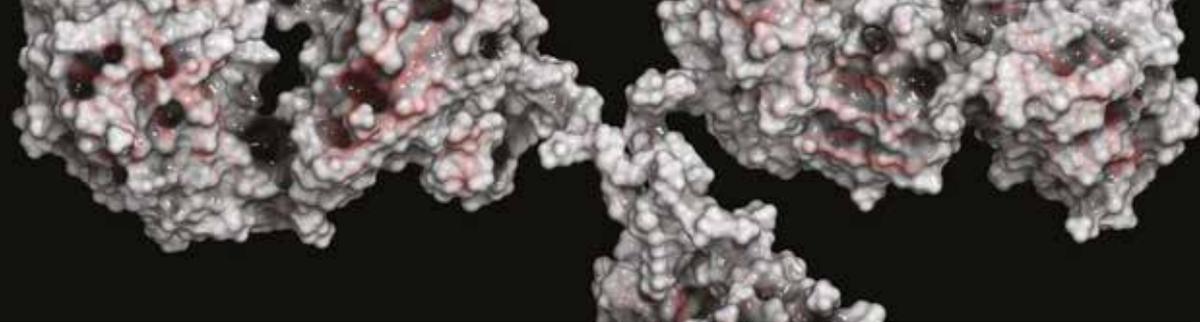
Pharmacokinetics

What the body does to the drug – the rate and extent to which drugs are absorbed, metabolised and excreted.

Efficacy

The ability to achieve the desired or intended effects of the drug.

The estimated cost of a new drug is £2.2 billion. This takes into account the drugs that fail in the testing phase



‘Because of the demanding regulatory requirements for biosimilar approval, people with lymphoma can feel confident when prescribed rituximabs that are biosimilar alternatives.’

acceptability criteria for generic versus biosimilar drugs (ie ‘virtually identical’ versus ‘highly similar’) is very subtle, and biosimilar drugs must still go through extensive state-of-the-art tests to prove their structural similarity to the original drug.

Furthermore, for approval of biosimilars, head-to-head clinical studies against the original drug must be carried out in at least one clinical scenario to demonstrate the similarity in terms of pharmacokinetics (what the body does to the drug – the rate and extent to which drugs are absorbed, metabolised and excreted) and efficacy (the desired or intended result of the drug).

In some of these studies the biosimilar molecule is actually found to be more similar to the original drug at the time it was approved than the current version of the original drug is to its first batches.

An area of controversy has been the concept of extrapolation, where a biosimilar shown to be effective in one condition is given authorisation for use in other indications for which no formal clinical studies have been performed. This is not automatic, and a sound scientific rationale for doing this must be provided to the regulators.

The introduction of biosimilars into the clinic is not new. There are many biosimilars already in use for other diseases; for example a biosimilar growth hormone, Omnitrope, was approved in the US in 2006.

The patent on rituximab (brand name Mabthera®) expired in Europe in November 2013 and in the US in September 2016. In Europe, marketing authorisation was given to one rituximab biosimilar at the end of 2016 (Truxima®, manufactured and marketed

in the UK by Celltrion/Napp) and another was recommended in April 2017 (named Rixathon® in the UK and manufactured and marketed by Sandoz). At least five others are in clinical trials in Europe and the US and more in the developing markets. For both of the approved rituximab biosimilars, the initial studies were carried out in rheumatoid arthritis, because there are a large number of patients with this condition in whom rituximab is used and because response assessment is possible in a short period of time.

Subsequently, both companies performed comparability randomised controlled trials (Phase III trials) in follicular lymphoma, enrolling 121 patients in the Celltrion trial and 629 in the Sandoz trial. The results of both trials were presented at the American Society of Haematology meeting (ASH) in December 2016.

The main parameters assessed were overall response rate and side effects, and no meaningful differences were seen. There has been considerable debate over whether this data can be used to extend the marketing authorisation to other types of lymphoma, such as the more aggressive diffuse large B-cell lymphomas (DLBCL). The European regulators have considered this at length and taken the view that such extrapolation is appropriate when the totality of the data is taken into account, including the very close

structural and functional similarities. The majority of haematologists and oncologists are increasingly in accord with this judgement.

In conclusion, because of the demanding regulatory requirements for biosimilar approval, people with lymphoma and chronic lymphocytic leukaemia (CLL), as well as rheumatoid arthritis and other auto-immune conditions (when the body's immune system, which defends the body from disease and infection attacks healthy cells), can feel confident when

prescribed rituximabs that are biosimilar alternatives to Mabthera®. Health providers, including the NHS, will benefit from the cost reductions associated with their introduction.



To find out more

To read the full article by Professor Linch, including references and a list of comparability tests typically performed, go to www.lymphomas.org.uk/BiosimilarsBlog

Your questions answered

What happens if I am already having rituximab?

Rituximab biosimilars are only given intravenously (through a drip into a vein). If you are already having intravenous rituximab, your hospital might want you to change brands if needed, eg if they don't have your current brand in stock. Your doctor can answer any questions you may have about switching brands. Only one brand of subcutaneous rituximab (given by injection under the skin) is currently available. If you are having subcutaneous rituximab you are likely to continue with this for your course of treatment.

What should I do if I have any problems?

You are monitored in exactly the same way regardless of which brand of rituximab you have.

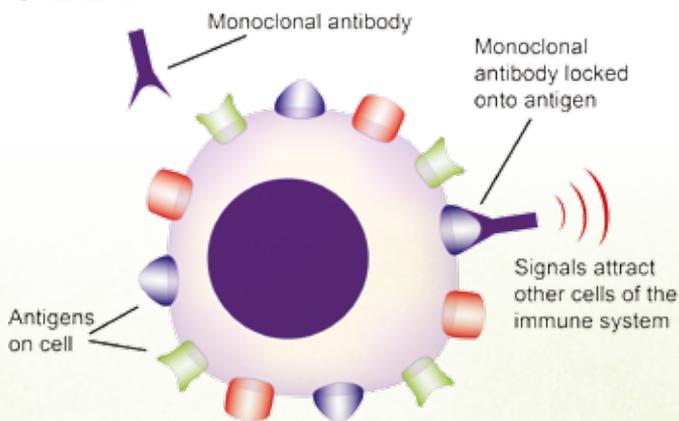


Figure: Cancer cell with surface antigens attracting monoclonal antibodies

All the brands of rituximab can cause similar side effects. If you experience problems with any treatment, report these promptly to your medical team. Talk to your doctor if you have a question about biosimilars or are worried about switching to a biosimilar.

The running *has begun...*

In March Lucy, Theresa, Paul and Neil all took part in the Silverstone Half Marathon. This was followed by the Paris Marathon in April, where both Thea and Thomas ran through the streets of Paris on a bright spring day.

28 runners took part in the 2017 London Marathon in support of the Lymphoma Association. The atmosphere was amazing, and we are really pleased that all our runners completed this inspiring challenge.

We send our hearty congratulations to Adam, Alison, Andy, Chris E, Chris H, Chris P, David, Deborah, Donna, James, Janet, Joanna, Katie, Leanne, Matt, Pamela, Paul, Robert, Robyn, Ross, Sarah H, Sarah W, Stuart, Tom B, Tom O, Toni, Vicky and Warren and thank them, their families and friends for all their support.



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To find out more about our walking, running, cycling and other events, visit www.lymphomas.org.uk/Fundraising or call us on 01296 619419.



To date all these amazing runners have raised more than £60,000 – a truly magnificent amount which will go to help others affected by lymphoma.

thank you



Talking about relapse

After a diagnosis of lymphoma, it is natural for people to be more aware of any aches and pains than they were before. Relapse is something people are concerned about and it can be very distressing if the lymphoma comes back. Many people are treated successfully if they relapse, with more and more treatment options becoming available all the time.

Most types of high-grade non-Hodgkin lymphoma and Hodgkin lymphoma are treated with the aim to cure. However, because of its chronic nature, the aim of treatment for low-grade non-Hodgkin lymphoma is to control the disease.

What is relapse?

Relapse is when lymphoma comes back after going into complete remission – that

is, there is no evidence of lymphoma. For low-grade non-Hodgkin lymphoma, relapse might mean the lymphoma has flared up after being stable for some time.

Why might lymphoma relapse?

Lymphoma treatments are usually most effective at killing fast-growing cells. Some of the slow-growing cells in low-grade lymphoma

may 'escape' treatment. When these cells build-up, a relapse happens. This is why relapse is more likely in low-grade lymphomas.

Since low-grade non-Hodgkin lymphomas grow slowly, most people only need treatment from time to time when their lymphoma gets worse. There are many good treatment options for low-grade non-Hodgkin

The range of treatment options is increasing and improving, meaning that periods of remission are becoming longer.

lymphoma and they can often be controlled for many years.

For most people with low-grade non-Hodgkin lymphoma, there will be periods when no treatment is needed. Instead, people are seen regularly in the clinic and monitored carefully. This is known as 'active monitoring' or 'watch and wait' and can last many years. Although low-grade non-Hodgkin lymphoma usually progresses after a quiet period of months or years, there are some people who may never need treatment for their lymphoma.

What happens when lymphoma relapses?

Lymphoma might come back where it was before or it could affect another part of the body, so symptoms may be the same as before or different. Contact your medical team if you have symptoms you are

worried about. They will either reassure you or organise an appointment for you to see your doctor.

If your doctor thinks you might have relapsed, you are likely to have tests, including blood tests and scans, as you did when you were first diagnosed.

How is relapse treated?

Relapse is distressing, but it is important to remember that relapsed lymphoma can be treated. Many people with low-grade non-Hodgkin lymphoma relapse several times and have several different treatments in the course of their illness. Indeed the range of treatment options is increasing and improving, meaning that periods of remission are becoming longer.

In most cases, there is not a standard treatment, but

treatment is based on your individual circumstances including:

- what type of lymphoma you have
- your symptoms and test results
- your general health and whether you have any other conditions
- what treatment you had previously and how well your lymphoma responded to it
- how well you coped with the treatment
- how long it has been since you were treated.

Treatment options for relapsed low-grade non-Hodgkin lymphoma might include:

- 'Watch and wait' for low-grade lymphomas if the lymphoma is not causing symptoms. Sometimes the lymphoma shrinks again without any treatment.



Carole

'I was first diagnosed with follicular lymphoma in 1984. I was told that I could relapse and at first I worried about that a lot. But with two very active sons, I decided life had to go on and I put any thought of relapse to the back of my mind. When I relapsed 10 years later, I realised that I had never really dealt with the emotional issues, and started to learn more about myself and my coping ability.'

- Radiotherapy if the lymphoma is localised to one or a few locations.
- Chemo-immunotherapy (chemotherapy with antibody therapy) – either the same regimen you had before or a different regimen.
- Antibody treatment on its own.
- A newer drug that is approved in the UK and funded by the NHS for some types of relapsed and refractory low-grade non-Hodgkin lymphoma.
- Other new treatments may be available through clinical trials.

Once the lymphoma is in remission, some people are offered maintenance antibody treatments, eg rituximab or a newer antibody like obinutuzumab. These treatments are given once every 2-3 months for up to two years to help keep the lymphoma in remission.



Sue

‘With lymphoma it has sometimes felt like two steps forward and one back. Rather like slow-witted cyclists on a tandem, eventually arriving at the top of the hill.’



Trevor

‘When I relapsed it became clear that a stem cell transplant was something I would have to go through.’

People who have had Hodgkin lymphoma or high-grade non-Hodgkin lymphoma

Most people who go into remission with Hodgkin lymphoma or high-grade non-Hodgkin lymphoma stay in remission. Only a small proportion of people relapse. However, some types of high-grade non-Hodgkin lymphoma are more likely to relapse, including:

- mantle cell lymphoma
- some T-cell lymphomas.

With Hodgkin lymphoma or high-grade non-Hodgkin lymphoma, relapse is more likely to happen within the first two years after treatment. As time goes on, relapse becomes less likely.

Some people don't respond well to their first treatment and don't go into remission. This is called 'refractory' lymphoma. Refractory and relapsed lymphoma are often treated in the same way.

Most people who relapse can have more treatment which can still be successful. If you relapse you are likely to be offered a more intensive treatment than your first treatment. It may be:

- A different type of chemotherapy.
- If you have a B-cell non-Hodgkin lymphoma (like diffuse large B-cell lymphoma or mantle cell lymphoma), you are likely to have an antibody treatment, eg rituximab, with your chemotherapy.
- If you are fit enough and respond to chemotherapy, a stem cell transplant may be possible.
- You may be eligible to take part in a new treatment that has become available. Speak to your doctor to find out.

Frequently asked questions

Can a relapsed lymphoma be picked up with a blood test?

Blood tests play only a small role in the diagnosis of lymphoma. For blood tests to be abnormal there either has to be involvement of blood, or the cancer has to be influencing the blood production; altering it in some way. This is rare in lymphomas, with only CLL, Waldenström's macroglobulinaemia and some types of splenic lymphomas involving blood.

However, blood tests have multiple components and look at other aspects of health, such as liver and kidney function, and the presence of certain proteins in the blood. This information is important, but doctors rarely pick up lymphoma through a blood test alone.

To get a clear picture your doctor needs to examine you, talk to you and carry out tests. A scan may be arranged if your doctor suspects a relapse of lymphoma. It is by putting all these elements together – tests, physical examination and discussion and scan results – that doctors get the full picture.

Are doctors looking for relapse at follow-up appointments?

Routine follow-up rarely picks up a relapsed lymphoma. If you have symptoms, feel unwell and have concerns about your health, contact your medical team straightaway.

I was diagnosed with lymphoma years ago when I found a lump on my neck. When I relapsed the lump appeared in a different place. Is this unusual?

Although there are specific areas where lumps are most commonly noticed (neck, armpit or groin), a lymphoma lump can result from a gathering of cells anywhere in the body. A relapse can appear at the same place as before or somewhere different. Likewise, you may experience similar symptoms to the ones you had in the past or different ones.

Symptoms to look out for

Contact your medical team if you have symptoms, feel unwell or have concerns about your health. Typical symptoms include:

Lump: an enlarged lymph node, resulting in a new lump which may be felt in the neck, armpit or groin

Cough or abdominal pain: sometimes lymph nodes can enlarge in areas that cannot be felt, which can cause symptoms such as a cough if they are in the chest or stomach discomfort if they are in the abdomen

Fatigue: feeling exhausted or washed out for no obvious reason

Unexplained weight loss: losing weight quickly without dieting

Itching: An itch, with or without a rash, which can be very troublesome.

Even if you experience symptoms, it may not be a relapse of lymphoma. Your lymph nodes will enlarge if your body is fighting infection, something that is a perfectly normal response. However, if you are concerned, contact your medical team and have it checked.

With thanks to Wendy White, Macmillan lymphoma and young person's nurse specialist at Queen Alexandra Hospital, Portsmouth for reviewing this article.



The Red Drug

Reem shares the emotional experience of having chemotherapy for Hodgkin lymphoma

‘The feeling of the needle going into my skin and veins was the easy part. ABVD chemotherapy was being given to me for the treatment of my Hodgkin lymphoma.’

‘I watch my nurse meticulously prepare the medication and she asks me if I am ready. For all of the cycles of chemotherapy, I was never ready.

I watched her as she inserted each drug, one after the other over a period of two hours. It was when the ‘red drug’ came that I glanced and a rush of dizziness and nausea swallowed me up. Was it the colour of the

drug making me feel sick? Despite the anti-sickness drugs, I found myself vomiting. The nurse stopped and waited until I became ‘stable’. This is hard. Why do we have to have cancer? I wasn’t even done with the second dose and I was already tired. The truth was, at that moment I wanted to stand up and walk away from it all. But my nurse always looked on the positive side of things, which I loved.

My vomiting gradually declined and my nurse explained that it was psychological as she had not fully injected the chemo yet. Two hours later I went home. I was feeling sorry for myself. The chemotherapy had engulfed me. My poor mother had to take me back to hospital that night. I knew she was fearful.

The next morning I sensed my consultant was briefed on

‘Sometimes the treatment itself is harder than the cancer and its symptoms!’

the state I was in and she came to counsel me. I cried and told her I couldn't take any more chemotherapy. She held my hand and said: "Reem you can. 10% is the chemo and the rest is you." At the time I didn't really understand what she meant.

I had 14 days before my next dose. I reflected, I prayed and I searched for a solution. **I found Yanni.** It was a CD that a girl at university gave me a few years back. At that moment, I listened and it comforted me. Two weeks later, with my head held high, I walked back to that hospital room, with its bare white walls, its 'comfy chairs' and its smell of chemo. I told my nurse that I was going to close my eyes and listen to my music. I told her, "Don't wake me until you have injected all the drugs."

Where did I go? As I listened to Yanni, I entered my interpretation of Heaven. It was where I wanted to be at the time; a beautiful garden filled with my freedom – free of the taste and smell of chemo.

For those who have been through cancer, or those that have supported someone going through it, you will recognise that it is not as simple as swallowing a tablet. Sometimes the treatment itself is harder than the cancer and its symptoms. If you are undergoing chemotherapy and are struggling to cope or feel helpless, just as I felt at the beginning of my treatment, then you can search for something that makes you happy and hold on to it with all your strength during your therapy.

For me, I prayed and entered my own world as the nurse injected the drugs. Despite the treatment, I began to reconnect with my zest for life and dreamed and visualised my future. I dreamed of a little girl with long smooth black hair. When I told my mother, she said she understood that I wanted to get through the treatment and not just to survive, but to thrive! The girl in my dream was me, with my long black hair back, having lost it during treatment. I visualised the girl often and this visualisation was a really important part of helping me heal. For me, it was my music, my mother and gradual faith that enabled me to get through it. I released the fear inside me and accepted where I was. I no longer fought where I was, but embraced it. I prayed and entered my own world as my nurse injected the drugs.'

Reem was diagnosed in 2006 when she was 25 years old. Ten years later, Reem explains that after her treatment for Hodgkin lymphoma she decided to change career and now teaches English and Media at 'A' level.



Did you know?

Nearly 2,000 people are diagnosed with Hodgkin lymphoma in the UK each year.



A background image showing a microscopic view of cells, likely lymphocytes, with prominent nuclei and varying sizes, set against a blue and purple gradient.

Update on newer drugs

Newer drugs are big news for lymphoma, particularly for people with low-grade (slow-growing) types of lymphoma. These targeted drugs can help people avoid some of the side effects of chemotherapy and provide more treatment options if lymphoma relapses (comes back).

2017 has already seen several drugs for lymphoma recommended for use on the NHS and the introduction of biosimilars for rituximab. However, some new drugs are available on the NHS only in certain parts of the UK. This article gives an overview of what's new in 2017 so far.

Ibrutinib for chronic lymphocytic leukaemia (CLL)

January saw the first National Institute for Health and Care Excellence (NICE) approval for ibrutinib in England. Previously available through the Cancer Drugs Fund, ibrutinib went into routine use on the NHS for people with **CLL** who have had at least one previous treatment or who have CLL with certain genetic changes (17p deletion or TP53) that mean standard treatment is not suitable for them. In April, the Scottish Medicines Consortium (SMC) recommended that ibrutinib be available on the NHS in Scotland for people with CLL

that has come back after previous treatment. CLL is the first type of lymphoma for which ibrutinib will be routinely available on the NHS across the UK. It is already available in Scotland for some people with mantle cell lymphoma. NICE decisions are expected to follow shortly on the use of ibrutinib for some people with **mantle cell lymphoma** or **Waldenström's macroglobulinaemia (WM)** in England.

Obinutuzumab with bendamustine for follicular lymphoma

In March, the Scottish Medicines Consortium

(SMC) recommended that obinutuzumab can be given together with bendamustine chemotherapy on the NHS for some people with **follicular lymphoma** in Scotland, namely:

- People who did not respond (refractory) to treatment with rituximab or a regimen (combination of drugs) including rituximab.
- People whose lymphoma progressed (got worse) during or up to six months after treatment with rituximab or a regimen including rituximab.

Successful treatment can be followed with obinutuzumab

maintenance (treatment to prevent the lymphoma coming back). At the time of writing, NICE had not issued guidance on whether obinutuzumab can also be used for people with follicular lymphoma in the rest of the UK.

Idelalisib for follicular lymphoma

In April, the All Wales Medicines Strategy Group (AWMSG) recommended that idelalisib be available on the NHS in Wales as a treatment option for relapsed and refractory **follicular lymphoma**. It is given on its own for people who have had at least two previous courses of treatment.

This treatment is already recommended for this use in Scotland, but it is not currently recommended for people with follicular lymphoma in England.

Brentuximab vedotin for classical Hodgkin lymphoma

Also in April, NICE released its final decision on funding of brentuximab vedotin in relapsed or refractory **classical Hodgkin lymphoma**. Brentuximab vedotin is available on the NHS throughout the UK for suitable people who have already had an autologous stem cell transplant.

People who have had at least two other courses of treatment and can't have an autologous stem cell transplant or chemotherapy with a combination of drugs may also be able to have brentuximab vedotin on the NHS. It is routinely funded for this use in Scotland, Wales and Ireland and is available through the Cancer Drugs Fund in England while more evidence for its use is collected.

Biosimilar rituximab

The first biosimilar for rituximab (Truxima®) was approved for use in Europe in December 2016 and a second (Rixathon®) was recommended by the European Medicines Agency in April 2017. These biosimilars will be alternatives to the original brand of rituximab, MabThera® and should drive down the cost of rituximab. Find out more about what biosimilars are and what they mean for people being treated with rituximab on page 10.

Hope and challenges

New drugs are exciting prospects for people with lymphoma as they can increase the range of treatment options, particularly for those with lymphoma that is difficult to treat or likely to relapse. However, frustrations remain over funding.

Ibrutinib (Imbruvica®) is a cell signal blocker that targets Bruton's tyrosine kinase (BTK). BTK is a part of the pathway that helps B cells to stay alive and divide. Blocking BTK promotes death of B cells, including lymphoma cells that develop from B cells, and prevents their division. This stops the spread of lymphoma cells.

Obinutuzumab is an antibody that binds more tightly to CD20 than does rituximab. CD20 is a protein on B cells. Antibodies that bind to CD20 attract immune system cells to destroy the B cells they are attached to. They also help the B cells destroy themselves.

Idelalisib is a cell signal blocker that targets phosphatidylinositol 3-kinase (PI3K), one of the steps in a pathway that helps B cells to stay alive and divide.

Brentuximab vedotin combines an antibody to the CD30 protein with a drug called monomethyl auristatin E (MMAE). The antibody delivers MMAE to the lymphoma cells reducing its effect on normal cells.

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



Find out more

For latest news on funding decisions read our blog at www.lymphomas.org.uk/LMblog



Micaela Plucinski is a Lymphoma Association clinical nurse specialist at UCLH, London. She provides expert knowledge and support.

Making sure people with lymphoma and their loved ones get the right information and support for years to come

Since 2010, legacy donations have contributed more than £1.5 million to the Lymphoma Association, which has enabled us to substantially grow as a charity and reach more people who need us. Legacies have a huge impact on helping us plan for the future, improve existing services and deliver new ones, including the provision of personalised online information.

‘I’ve been working with the Lymphoma Association since 2006, when the clinical nurse specialist service was set up, and they helped to fund my role. I’ve seen the clinic grow in size and patient numbers from around 30 per week nine years ago, to nearly 100 per week today.’

Micaela and her colleagues see people every day who simply couldn’t have coped without the support of the Lymphoma Association.

‘We’re there when people receive their diagnosis and provide support from then on. People are often stunned and forget to ask questions of their doctor during consultation. I always mention the Lymphoma Association to people, as the written information they provide is of such high quality. I use it every day. I also encourage people to access their Buddy scheme which is a great service. Knowing someone has been through the same thing can be invaluable for people. If someone is feeling isolated, I also mention the Lymphoma Association Support Groups.’

Legacies are vital in funding these much-needed services and give hope and support to people affected by lymphoma and their families.’

Every legacy donation, no matter how small, really does make a difference. It costs nothing during a lifetime, yet it represents a tangible commitment to the future of the people who need us. At times, legacies have saved our services from being cut.

We know that your will is your own private matter, but if you are able to include us after taking care of your family and friends, you’ll help empower people facing lymphoma in the future to face it with more confidence, strength and knowledge. Thank you.

For more information on how to make a gift in your will, please visit www.lymphomas.org.uk/Legacy or call us on 01296 619419 for a free, no-obligation legacy information pack.



Did you know?

Every year in the UK more than 19,000 people are diagnosed with lymphoma (including CLL) making it the fifth most common cancer diagnosed overall.



Considering carers

What is a carer? Here we consider a carer to mean a person close to someone affected by lymphoma who takes an active role in their care. They may be a partner, parent, child, family member or friend. The term can apply to anyone supporting a person affected by lymphoma.

A diagnosis of lymphoma brings changes

A cancer diagnosis brings many changes. Plans, hopes and dreams may need to be altered, just like that. Roles can change dramatically, with one person becoming more dependent on the other. This may be a difficult shift for everyone involved.

There may be a range of emotions including anger, resentment, guilt, hopelessness, along with low mood and anxiety. These

emotions are natural and need to be acknowledged. You may find it helpful to talk to others about how you feel, including those who are going through something similar. Relaxation techniques, such as mindfulness, may be helpful.

Making plans, offering to help

One of the most important things may be to spend time with the person with lymphoma and be there to listen. It may be really helpful

for them to have something to look forward to, so make plans, for example, go out for a coffee or a walk.

It can be hard for someone to admit they need help, even when it's offered. Being specific with your offer may make it easier for them to accept. For example, 'I'm popping into the shops this afternoon, is there anything I can pick up for you?'

If you offer to help and they say 'no', ask again later, as

Talking about your worries can help to make sense of what you are both experiencing and make you both feel less alone.

their needs may change. Consider what type of help you can offer, such as driving the person with lymphoma to an appointment, mowing the lawn or childcare, for example, and don't be afraid to ask what type of help they may find helpful. But don't be upset if they don't accept help.

Why talk?

Lymphoma and its treatment can present many challenges. Your partner, relative or friend may have many concerns and worries – how they will cope with treatment, the effect on work and finances, concern about side effects, changes to their appearance etc. They may want to protect you from the emotions they are feeling or worry about burdening you with their experience.

You may feel it is hard to talk about these things openly. You may also have your own thoughts, feelings, fears and anxieties about the lymphoma and its impact on your life as well. Often people think it is best to stay stoic, but this may be difficult on both sides.

Talking about your worries can help to make sense of

what you are both experiencing and make you both feel less alone. It will help you better understand each other's perspective and to acknowledge each other's feelings. This in turn can help you both to cope with your own feelings, get rid of misunderstanding and bring you closer together.

Making yourself available

Show you are there for the person with lymphoma. Even if you don't know what to say, you can show your support simply by being there, listening and making them leave the house. Non-verbal clues like touch, smiling and nodding to reinforce a message show that you are offering your support. If the person you are caring for does not want to talk, let them know that that is alright, but that you will be available if and when they do. If you don't live with the person with lymphoma, ask them how they would prefer to communicate. If they are tired, they may prefer to receive text messages, emails or talk on the phone.



A well-timed hug can be massively reassuring

Listening

When the person with lymphoma wants to talk, try to stay with the subject, and not say 'you'll be fine' or try to find a practical solution, when the person just wants to talk. Allow your loved one to be sad or upset. People with lymphoma sometimes hide their feelings, and it can be helpful to be allowed to drop this mask. Crying often helps to release tension. Acknowledge how difficult the situation must be and try not to dismiss the issues they are facing. If you are unsure about what they are saying, ask follow-up questions and repeat back what you've heard to acknowledge you understand what they mean. Be guided by the person with lymphoma about how much they want to talk, and remember they may prefer not to talk about their health.

Giving advice

Give advice carefully and

don't be afraid to say: 'I don't know what to say.' Stick to what you know, but if there is a practical problem to be solved, thinking and working through it together can be helpful. If your loved one is struggling emotionally, you might suggest asking for psychological support, counselling or consider attending a support group. Suggest they talk to health professionals, including GPs, about how this sort of support can be accessed, and speak with the medical team about any health-related worries.

Hospital appointments and understanding lymphoma

If you are attending hospital appointments together, it can be helpful to talk through the meeting beforehand, prioritising what needs to be discussed during the

meeting. It may be useful to make notes of questions and concerns to take into the meeting. Encourage the person with lymphoma to ask about anything they are worried about, such as symptoms, treatment or side effects.

You may find healthcare professionals use terms that neither of you understand. Don't be afraid to ask what the terms mean and if you are uncertain you could say something like, 'Now let me check I understand.' Talk about the hospital appointment afterwards to make sure you both picked up the same message from the meeting. It's an opportunity to discuss any thoughts, worries or expectations about the appointment.

Sharing information

It is up to the person with lymphoma to decide how much they want to share with others. Some people involve their partners, friends and relatives in their care, but others prefer not to. There may be a number of reasons for this. They may be very independent and want to take full control of their health or they may not want to burden others. It might be that they are not ready for all the information, or they may still be adjusting to their diagnosis. This can be hard to understand if you care for them and are not as involved as you would like to be. Try to take a step back and wait for the person with lymphoma to come to you.

Monitoring the health of the person with lymphoma

After a diagnosis of lymphoma, people are often on the look-out for signs of infection or relapse. They should have been advised what to do in case of problems.

As a carer, you may also be in a good position to observe symptoms, and can gently point them out if they have not been registered. You may also have read more around the subject, so may be able to spot the possible signs.

Signs of infection

include: fever (a temperature over 38 degrees C), shivering, chills and sweating, feeling generally unwell, confused or disoriented, earache, cough,

Get support for yourself

A diagnosis of lymphoma can bring people closer together through a shared focus; more time spent together, a reassessment of what is important in life and a new appreciation of strengths and values. But it can also be exhausting and stressful for some people, and they may feel that their needs are not so important at this time. In fact, it is crucially important that carers look after themselves properly, for both themselves and for the person with lymphoma.

Pay attention to your own feelings and make sure you still make time for yourself. Eat and drink healthily and make sure you get enough sleep. Don't take it all on yourself: ask for help from family and friends and be prepared to let some tasks go to other people. Organisations such as Carers UK, Maggie's and the Citizens Advice Bureau can help you to deal with financial problems and queries about benefits. If you are still working, talk to your employer about carer's leave.

Read more at www.lymphomas.org.uk/Carers



'As a retired Occupational Therapist, you'd think I would feel comfortable in hospital, but it didn't make it any easier when it was my daughter who was being treated for her lymphoma. I learnt a lot about her condition as any booklets she was given were handed straight over for me to tell her just what she needed. She simply didn't want to know!' Helen with daughter Carol

sore throat or mouth, redness and swelling around skin sores, injuries to intravenous lines, diarrhoea, a burning or stinging sensation when passing urine, unusual vaginal discharge or itching, unusual stiffness of the neck and discomfort around bright lights.

Signs of a possible relapse

include: swollen lymph nodes, fatigue, unexplained weight loss, night sweats, persistent infections and itching. The lymphoma may not present with the same symptoms as before, so encourage the person with lymphoma to seek help if suspecting a new symptom.

Living with uncertainty

Many people living with lymphoma – whether as the person with lymphoma

or their carer – are living with uncertainty, which can take away some of the sense of control in life. You can try to learn to live with uncertainty with techniques like mindfulness meditation. For some people, taking action despite uncertainty, for example planning a holiday after treatment, can be helpful.

Coping with side effects

The aim of treatment for lymphoma is to destroy all of the lymphoma cells. However, treatments for lymphoma have other, unwanted, effects on the body called 'side effects', which for some people are mild, while for others are more troublesome.

There are practical things that can be done to better manage some side effects of treatment, for example

exercise can help with fatigue – maybe encourage them to go for a walk with you. Hair loss can affect a person's self-esteem and lead to them avoiding seeing people. It can help to talk to them about this, and to work on ways to counteract it and build up the person's confidence by focussing on skills, achievements and value.

Watch and wait

For people on watch and wait (or active monitoring), getting on with life can have challenges. If treatment has been given, the person with lymphoma may then feel abandoned by their healthcare professionals and may worry about their lymphoma returning. It can be difficult to accept a chronic illness when there aren't any symptoms, and there is nothing you specifically need to do. It can be hard to make plans when you worry that the lymphoma will return.

It is useful to accept that this can be a difficult time for you both, and adjust your expectations about what is a normal life now. It may also be a time to think about building up activities again. It may help to talk about the things you both enjoy or want to achieve at this time, and start to work towards these goals.

With thanks to Dr Maggie Rayfield, Lymphoma Association clinical psychologist.

‘In July 2014, at the age of 72, I started to feel really exhausted. I visited my doctor who thought it could be an infection, but this exhaustion got worse, so I went back to my doctor who arranged more blood tests. These showed I was type 2 diabetic. I thought they’d got to the bottom of the problem, especially as both my father and sister had type 2 diabetes. I was

masseuse found a lump in my neck she said I should see my doctor. My GP referred me to an ear, nose and throat (ENT) specialist for the lump and to a gastroenterologist to see why I was having such problems eating. I had a fine needle biopsy taken from the lump in my neck and a chest X-ray to investigate my breathing problems.

tube because I still couldn’t keep any food down.

I was in hospital for nine weeks and the diagnosis was confirmed as **diffuse large B-cell lymphoma**, a high-grade non-Hodgkin lymphoma. My health was gradually improving which was necessary for the R-CHOP chemotherapy. I was in hospital for the first two cycles and at one point

‘I thought a diagnosis of diabetes explained how ill I felt.’

prescribed Metformin and looked forward to feeling considerably better.

I felt so confident that my health would improve, I booked a trip to New York where my son lives. I felt a little better over the two weeks I was there, but on my return my health went rapidly downhill. I couldn’t eat anything, had no appetite and was losing weight rapidly. The exhaustion that I’d hoped would improve got worse, breathing was difficult and I was struggling to walk even a short distance. Clearly there was something else wrong.

I had gone for a massage in November and when the

While waiting for the test results, I seemed to get far worse; I was struggling to breathe and couldn’t eat or drink. I had also developed a cough which had gone on for over 4 weeks. My daughter insisted on taking me to A&E where I had all sorts of tests. I was admitted into haematology. I had the lump in my neck removed for biopsy as well as blood tests and a CT scan. This revealed that I didn’t have just one lump in my neck, but lumps on the other side of my neck, in my abdomen, my chest, groin and armpits. I needed to have fluid drained off my lungs, which was the reason I was struggling to breathe and I was fed through a nasal

I was unable to do anything for myself. I lost the use of my legs, my bladder and my bowel. Although I had expected to lose the hair on my head, I was shocked to actually lose all my body hair.

I became very depressed. I didn’t want to become dependent on people and be unable to do anything for myself. I was walking with a frame but felt so fatigued I had no interest in anything. At first I refused to have the second cycle of chemo but one of the consultants explained that I was already a long way through my treatment and helped me feel that I shouldn’t give up.

Looking back now he was right. I really wish at that time I had someone to talk to who

had been through this. I didn't know about the Lymphoma Association or its Buddy scheme, but I would have found it enormously helpful.

I went home before my third cycle of chemotherapy and one of my granddaughters, who was 16 at the time, moved in with me for the first two weeks. She was able to help me get dressed and washed, help with my feeding tubes and the drugs I needed to take. She was marvellous. I seemed to pick up an infection after each chemotherapy and had to be admitted into hospital several times. Apart from exhaustion, I also developed pulmonary embolisms in my lung so had to go on anticoagulants. The chemo also affected my nails and I developed peripheral neuropathy in my toes. After six cycles of R-CHOP I had a

Get in touch if you'd like to be put in contact with one of our Buddies, who have personal experience of lymphoma. They're not trained counsellors or medical experts, but they do understand what you're going through and can offer support.

PET scan. I had lumps deep in my abdomen which had not gone, but they had not grown and were not active. My consultant discussed my case at a multidisciplinary team (MDT) meeting and it was agreed to stop treatment rather than carry on with another two cycles of chemotherapy, which could have done more harm than good. Knowing that four consultants discussed my case was really reassuring and gave me confidence that this was the best decision in my case.

Once I had finished chemotherapy my body became stronger and coming

off the feeding tube felt like a real step forward. While undergoing treatment my type 2 diabetes was controlled with insulin, but I was able to return to an alternative medication afterwards.

Since treatment, I have visited my sister in Scotland, taking my granddaughter with me and even went to New York to visit my son, taking my other granddaughter. Travel Insurance was very expensive but at least I was covered.'

Frances

Almost 1 in 3
people with
NHL will have
DLBCL



'When I left hospital, my granddaughter moved in to help me manage. She was marvellous.'

Frances (centre) with daughter Caroline and granddaughter Chrissie

Lymphoma Association Support Groups near you

Aylesbury
Bangor
Bath
Cambridge
Canterbury
Cardiff
Cheltenham
Colchester
Colne
Coventry
Driffild
Frodsham
Glasgow
Guildford
Ipswich
Isle of Man
Kendal
Lancaster
Leeds
Leicester
Macclesfield
Manchester
Milton Keynes
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)
Wigan
Lymphoma Association Support North West (closed Facebook support group)
Lymphoma Association Support South West (closed Facebook support group)



Support Groups



Developing listening and questioning skills

Buddy refresher day

Our Buddy refresher training was held the day after the National Conference, making a weekend of it for those attending. We covered important skills such as listening and questioning, the importance of confidentiality, safeguarding and the use of social media. We received a lot of comments about the growing number of requests for buddying by email, and identified a need for having specific training for this method of communication at future Buddy days.

Third Support Group in Cheshire

We are delighted to announce that there will be a new Support Group launching in Macclesfield on Tuesday 4 July at 5.30pm. The group, which will be our third in Cheshire, will be held in the Macmillan Centre at Macclesfield District General Hospital every three months. We would like to thank the team at Macclesfield for their support.



If you'd like to know more about lymphoma or news about the Lymphoma Association there are lots of ways to get information and support:

Web: www.lymphomas.org.uk

Phone: 0808 808 5555

Email: information@lymphomas.org.uk

Text: 07786 202030

WhatsApp: 07494 181130

Facebook: @LymphomaAssoc

Twitter: @LymphomaAssoc

Instagram: @lymphoma_association

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@lymphomas.org.uk or visit our website at www.lymphomas.org.uk/LASupportGroups.

Fantastic first meeting for Isle of Man

The launch of the Isle of Man support group in April was a great success. The group, which is the only blood cancer support group on the island, will meet every three months at Manx Cancer Help, Cronkbourne. The clinical nurse specialist from Nobles Hospital will join the next meeting on Wednesday 19 July at 5pm.

Leeds group – change of venue for summer meetings

Instead of daytime meetings at St James Hospital, this summer the group will be meeting at the John Lewis Community Hub in Leeds from 5-6.30pm on Monday 26 June and Monday 31 July.



New group opening in Ipswich

We have new Support Groups starting up all over. Our first group in Suffolk launches on Thursday 22 June at the John Le Vay Cancer Support and Information Centre at Ipswich Hospital, and will be meeting every other month from 7pm. As with all our groups everyone affected by lymphoma is welcome, whether you have the diagnosis or someone close to you has.

Relaxing exercise session for Sutton Coldfield Support Group

Hot on the heels of our National Conference Wellbeing Weekender, members of the West Midlands Support Group in Sutton Coldfield took part in some relaxing chair yoga. The yoga practitioner tailored the session to the needs of the group, including those currently having treatment.

'I found the session very good, I've never tried anything like that before and found it incredibly easy to suddenly relax. The feeling was unusual for me and it's certainly something I want to pursue.'

Andrew





Jilly Vickers

Development Manager for the South East and London

Our new Development Manager in the South East and London regions is Jilly Vickers. Jilly has spent more than 25 years in the voluntary sector, including a decade in regional development, most recently in the criminal justice sector, and before that in housing and the homeless. She is looking forward to developing work in the regions started by Denise Crone and to work with Support Groups, volunteers and health professionals in London and the South East.

Vote for your 2017 *Beacon of Hope*

Do you know someone who has made a difference to people affected by lymphoma? Do you think they are deserving of an award?

If so, nominations for this year's Beacons of Hope Awards can now be submitted online at www.lymphomas.org.uk/BOHA

You can nominate anyone in the UK, whether a patient, friend, family member, carer, partner, fundraiser, health professional or even a ward in your local hospital. This year's ceremony will take place in November. More details will be announced on the *Lymphoma matters* blog in the coming months.

Written applications are also welcome. Please contact communications@lymphomas.org.uk



Lymphatic Cancer Awareness Week, 11-17 September 2017

This year, the theme of our Lymphatic Cancer Awareness Week campaign is Lymphoma – what matters? It is for people diagnosed with lymphoma, their family, friends and carers and healthcare professionals. We will be inviting everyone affected by lymphoma to tell us what matters when it comes to awareness-raising, diagnosis, treatment, and aftercare of lymphoma. We want to

understand how people are affected by a lymphoma diagnosis, but also what needs to change to better serve and support them. And of course we will still be carrying out all our awareness-raising through social media, events and the press. If you would like to be involved or kept up-to-date as we develop the campaign, please drop us an email at LCAW@lymphomas.org.uk.



The Wellbeing Weekender and conference

More than 200 guests joined us for our 2017 National Conference, which we ran in parallel with our first ever 'Wellbeing Weekender'.

We organised accommodation and spa treatments and expanded our usual conference programme to include wellbeing taster sessions.

Our outstanding medical talks were complemented by mindfulness, Nordic walking, yoga for cancer and crafting and crocheting taster sessions.

80 guests attended our conference dinner, enjoying the time to socialise and share their experiences. Russell Taylor, whose story appears on page 6, gave an honest, heartfelt after-dinner speech which served as a great reminder that laughter is often the best medicine!



Later this year we will be holding regional conferences in Belfast, Portsmouth and Hull. For all the latest information on upcoming conferences, visit www.lymphomas.org.uk/LAConferences.



Our medical advisory panel Our work is fully supported by members of our medical advisory panel who assist in the development of our publications, review our information, advise on our services, provide training and contribute to our conferences and study days. The full list is available at www.lymphomas.org.uk/MedicalPanel

We are here for anyone who needs lymphoma information and support.

Would you still like to receive *Lymphoma matters* magazine? Please let us know.

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