lymphoma MATTERS

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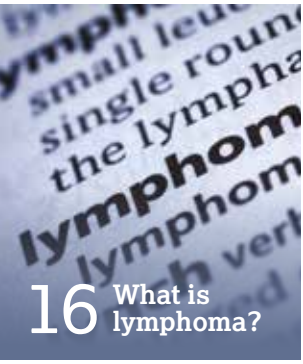
FOCUS

Lymphoma – back to basics

Talking to a child about lymphoma

Lymphoma association



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The Lymphoma Association is a specialist UK charity that provides medical information and support to people with lymphoma, 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.

Cover: 'Make Blood Cancer Visible' art installation in Paternoster Square, London. See page 4.
Photo credit: Mark Cocksedge

Editor: Anne Hook

Read the latest news on our Lymphoma Matters blog online www.lymphomas.org.uk/Blog

Lymphoma association

Jonathan Pearce
Chief Executive

@JPearceCEO

Read more about new treatments discussed at an international lymphoma meeting on pages 26-29.

We hope you like our magazine. Don't forget to opt-in to receive future issues.

A complex disease

In this issue you will find articles about people's experiences of living with lymphoma, covering different subtypes, different perspectives and the different circumstances in which they find themselves. There are also articles about the dizzying pace and complexity of lymphoma research and clinical and scientific advances.

Although lymphoma is the fifth most common cancer, in reality, as Professor Kristian Bowles points out in his article, it is not one cancer. It is an umbrella term that covers a large group of related but different diseases. So, even though there are many new exciting treatments being developed for all sorts of subtypes, it can be hard to get them into routine use on the NHS. This is for a whole range of reasons, including the challenge of assessing the clinical and cost-effectiveness of medicines for relatively small subtype populations. The numbers of people affected make it difficult, and often unethical, to carry out Phase III randomised controlled trials before seeking regulatory approval. And of course the initial market price of the treatments is a major issue for the NHS.

Yet, as was discussed at a recent meeting I attended and presented at in the Scottish Parliament in September, people need new treatments to be approved for use on the NHS quicker than is currently happening. This is not just because it gives people with lymphoma more treatment options, but also because it gives clinicians the opportunity to learn more about how the treatments work in the real world, not just in the world of international clinical trials.

Some of the people affected by lymphoma whose names appear in the installation

Photo credit: Janssen

Art installation to 'Make Blood Cancer Visible'

To mark Blood Cancer Awareness Month this September, the Lymphoma Association – along with eight other blood cancer charities – took part in a campaign to raise awareness.

The *Make Blood Cancer Visible* campaign was sponsored by pharmaceutical company Janssen and supported by the Lymphoma Association, Bloodwise, Leukaemia Care, Myeloma UK, CLL Support Association, WMUK, Anthony Nolan, MDS Foundation and CML Support.

As part of the campaign, Janssen commissioned designer Paul Cocksedge to create an art installation that featured 104 large three-dimensional names in Paternoster Square, London (pictured on the front cover). Each of the sculptures represents one of the 104 people diagnosed with a blood cancer every day in the UK. They were created from the first names of people who agreed to participate. Each stands the height of the named individual and includes brief details of the person's experience of being diagnosed with a blood cancer.

Janssen also commissioned two public surveys carried out by YouGov that revealed that less than a third of the British public know that lymphoma and multiple myeloma are common types of blood cancer, and that only one in 10 people are aware that there are over 100 different types of blood cancer. Only 12% of survey respondents selected blood cancer as one of the top five most commonly diagnosed types of cancer.

Jonathan Pearce, our chief executive, said: 'We were delighted to be involved in this campaign. Lymphoma is the most common form of blood and lymphatic cancer, yet public awareness is low and we need that to change. We hope that by being part of this campaign we have helped to make blood cancer a bit more visible, and that more people will now visit their GP if they are experiencing any of the signs and symptoms.'

2016 Awareness campaign recognised in Awards

Our *What's your type?* campaign, launched during Lymphatic Cancer Awareness Week 2016, was a finalist in the Communiqué Awards 2017. These awards recognise excellence in healthcare communications since 1997.

We were shortlisted in the *Charity, Patient or Professional Association of the Year* category after providing details about the success of the *What's your type?* campaign.

Denise Harkin, our senior marketing and communications manager, said: 'Lymphoma is a complex disease with more than 60 subtypes – it's important that patients know their type of lymphoma as it has an impact on their treatment and outlook.

'We were very proud of the simplicity of this campaign – taking something very complex and making it easy for people to ask about and record. We were delighted to see our work recognised in this way.'

Newly formed blood cancer Parliamentary group to publish report

The new All Party Parliamentary Group on Blood Cancer (APPGBC), which formed in June, is set to publish a report later this year drawing upon written and spoken evidence provided by a range of stakeholders.

Earlier this year, the APPGBC launched an inquiry that sought to look at all aspects of blood cancer, including awareness, diagnosis, patient experience, commissioning of services and clinical research. They wanted to learn more about the care patients are receiving, as well as identify areas of best practice and make recommendations for improvement.

The first phase of the inquiry invited patients, carers, charities and health professionals to submit written responses to questions about blood cancer diagnosis, treatment and aftercare. The second phase saw two evidence sessions take place in Parliament in September at which MPs from the APPGBC heard from clinical experts about what needs to improve in blood cancer care. The sessions also gave MPs an opportunity to ask questions about the specific areas of blood cancer in which they have an interest.

A formal Parliamentary report that captures the views of patients and clinicians is now being developed and is expected to launch in the coming months.

Erika Murigi, our PR and public affairs manager, said: 'We hope the publication of a formal Parliamentary report will help raise awareness of the issues facing blood cancer patients and drive MPs and policymakers to investigate specific areas of policy and practice.'

We will provide details on the Lymphoma Association's response to the enquiry and how to access the report once it is published on our website.

Who Cares?

Report reveals lack of post-transplant services

A new research report from the Anthony Nolan charity entitled *Who Cares?* has revealed patients don't always have access to the care and support they need following a stem cell transplant.

In response, Anthony Nolan has launched a campaign calling for an urgent review of the commissioning of post-transplant services. In *Recovery after Transplant – Who Cares?* the charity reports that significant improvements are needed in the commissioning of post-transplant services and that the failure to plan and pay for appropriate care is increasing the burden on patients and their families, making recovery more difficult.

To learn more, visit www.anthonynolan.org/whocares.

Professor Sir John Temple with members of the publications team

Lymphoma Association wins BMA award

We are delighted to announce that the Lymphoma Association won first place at the British Medical Association (BMA) 2017 Patient Information Awards for 'Information for young adults'. The BMA described the *Young person's guide to lymphoma* as:

'…an outstanding publication. The content, layout, design, use of colour and navigational aids are exceptional. It has a real "pick me up and read me" feel to it, which I would see as particularly important given the age range of the target population. Exceptional in every way.' This booklet couldn't have been produced without young people who shared their experiences, expert medical advisors who gave their time and expertise and an excellent designer who helped us bring the booklet to life'. Thank you to everyone involved.

New treatment combination for follicular lymphoma

European approval of obinutuzumab in combination with bendamustine chemotherapy was reported earlier this year for some people with follicular lymphoma that had relapsed (come back) within 6 months of treatment with rituximab or was refractory (didn't respond) to rituximab.

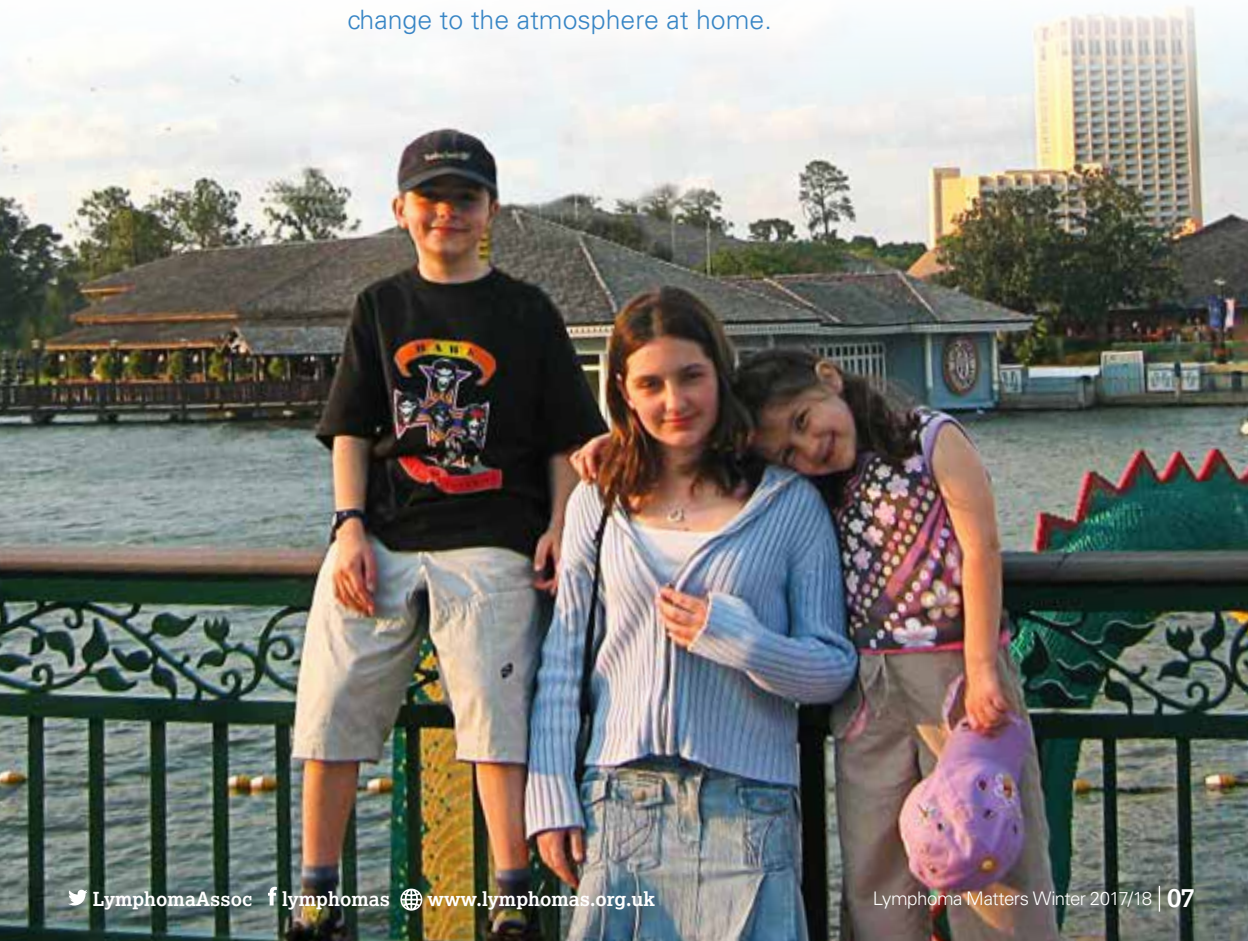
In March 2017, NHS Scotland recommended this treatment for use on the NHS in Scotland.

In August 2017, the National Institute for Health and Care Excellence (NICE) also recommended this treatment for use in England.

Obinutuzumab with bendamustine will be available on the NHS through the Cancer Drugs Fund (CDF) while more evidence is being gathered for its use. Obinutuzumab is also being assessed for use as a first treatment for follicular lymphoma with a decision expected in January 2018.

Talking to a Child about lymphoma

If you or a member of your family have lymphoma, then to support children it's best to be open and honest. Even very young children can pick up when something is going on in the family. They can tell the difference in how people talk to each other and sense a change to the atmosphere at home.



Children's thoughts can often escalate and give them a sense of fear. The way to prevent this is to sit them down quietly somewhere where you all feel comfortable and explain that mum, dad, grandma or grandpa is not very well at the moment. How much detail you tell them at that moment depends on their age and ability to understand this information.

Talking to children and helping them understand what may happen during someone's illness is really important. This can help prepare them for any changes that may occur, and reduce their fear. There can be alterations in appearance such as weight loss, hair loss or fatigue for example. For a while you may not be able to do many of the things you used to do together, such as taking them to school, getting involved in their activities or even just going out with them. It is really important children understand that this is all part of the process.

'Puddle jumping'

What we describe as 'puddle jumping' is when children become really upset and distressed and then the next moment they are running down the garden and playing on the swings quite happily. This is perfectly normal behaviour and is how children process information. Don't be alarmed if they are not reacting as you would expect. Just be there for them and encourage them to talk and ask questions. If you don't know the answer, it's OK to say: 'Actually I don't know the answer to that, but it is a really interesting question. I will see if I can find out.'

Siblings

When talking to children, it is really important to make sure they all have the same information. This can be quite challenging when you have children of varying ages and developmental stages.

It is helpful if you can all sit down together and talk, using language that the youngest of the children will understand. If the older children want to ask more complex questions, then try to help the younger children understand what is being asked in simpler language. It is important to use the correct words, so that there is no confusion; children take information literally. Don't say that 'grandma has gone away for a while', when in fact she is in hospital. By doing this, when someone else in the family is going away, such as on holiday, it will create anxiety.

Routines can change, and while they are important for children, it is always helpful to manage their expectations on how things might be different. For example, you may need to ask someone else to pick them up or drop off at school. Help them to understand the reasons you need help at this time and be clear on what the plan is. It may be helpful to reinforce this information on the day, so that they have expectations of what's happening to them, where they are going and when they will be collected to go home. This will help them manage their emotions and instil a sense of control and calm for them.

Reflecting our behaviour

How we behave in front of children is key. For our children or grandchildren to be able to express themselves, they need to see us do so as well. It is OK to be emotional and shed a tear, to show emotions and not bottle them up. Holding in our feelings can make communications more difficult. It can also lead to health problems such as depression and sleep difficulties.

Clear communication

Ongoing communication is vitally important. Even though a child may not be in the room

when you are having a conversation with someone else, they often pick up bits and pieces of discussions. This can be very harmful to a child if they think you are trying to hide something from them.

Explain what they can expect

It is really helpful to explain to children what they can expect. For example, if you are going to be taking a child into hospital to see a grandparent, talk through what they can expect to see. What is the environment like? Is it a room or a ward with several people? What will it look like? Will there be medical equipment around? What will it smell like? Explain to them that there may be other people coming and going, such as nurses, doctors and other visitors. Helping them to understand what they may see and experience is really important. They can then make a choice about whether they are comfortable going into that environment. It is important that children can choose what to do.

It is unhelpful to force a child into a situation where they feel uncomfortable; it is something they will remember. Allow them to make an informed choice and encourage them to say if they change their mind at any point. This is all part of their emotional development. If we support them in the right way, we can give them the tools they need to get through other difficult situations in their life.

It is important that children can choose what to do.

A diagnosis and treatment for lymphoma can be a very difficult and challenging time for families. Remember there are other resources and help out there. Counselling may be helpful for individuals and a family. Other resources you may want to consider are your friends and family, workplace support, church, school or groups like brownies. They will be able to support you and will understand that things are difficult and that your child may need additional nurturing or attention.

Read more

Read Katherine's story about being a mum with lymphoma on page 22.

With thanks to Claire Tune, Lead Counsellor at Phyllis Tuckwell Hospice Care, Farnham

models are used in this photo

Taking a step back

Pam talks about her diagnosis of extra-nodal marginal zone lymphoma

All I had was a runny nose. It sounds ridiculous, but as a yoga teacher I am upside down more often than most people and it was really unpleasant for me – and for my clients!

I tried Sudafed, but it made no difference; I got to the stage where I was going to bed with a hanky up my nose!

I went to my doctor, who thought the symptoms were really unusual, so sent me for a chest X-ray. A few days later the doctor called to say they needed to carry out further tests as they saw something on my lungs.

At this stage, there was no mention of cancer, but instinctively I knew it could be something serious. A CT, followed by a PET-CT, showed that my lungs, liver and neck were affected. They said they suspected it could be lymphoma, but would need to carry out a biopsy to make a diagnosis.

I was transferred to the haematology department where the biopsy was carried out. They used local anaesthetic, so the procedure wasn't painful, but I felt a thudding sensation as they took two separate biopsies from close to my breast bone.

On 6 June 2016, I was diagnosed with stage 4 extra-nodal marginal zone non-Hodgkin lymphoma. It was in my lungs, liver and in my neck.

It was the year of my 50th birthday and I had planned all sorts of things to celebrate. This was a bolt out of the blue and despite my suspicions, nothing prepared me for the shock of the diagnosis or the impact it had.

I asked my dad to go to the appointments with me. I wanted someone with a clear head. He was there as my advocate, asking all the questions that weren't coming into my head at the time. I just felt so shocked and upset.

Having read up about extra-nodal marginal zone lymphoma, I felt fairly certain they would recommend a period of 'watch and wait', which I was happy to do as I understood the reason for this approach.

I had not expected to talk about chemotherapy immediately and felt nervous about the use of such toxic drugs, especially as the strongest thing I'd had before was paracetamol.

Did you know?

Our *Live your Life* and *Working after Cancer* workshops support people affected by lymphoma. See page 35 for dates.

Read about other side effects of treatment at www.lymphomas.org.uk/side-effects

More about peripheral neuropathy

Peripheral neuropathy (PN) is damage to the nerves of the peripheral nervous system which is the network of nerves outside of the brain and spinal cord.

Symptoms of PN depend on which nerves are affected, but it is fairly common to experience pins and needles, numbness or a burning sensation, pain and increased sensitivity to touch and temperature. If you have PN, you may have difficulty with tasks that need fine movements, such as doing up buttons or tying shoelaces.

Usually, the symptoms of PN go away once you finish treatment for lymphoma, although they can go on for longer. Improvements in symptoms may continue for up to a year after treatment; further improvement after this time is unlikely.

Tell your doctor if you think you might have PN. They can look at how to prevent further nerve damage, which may involve tweaking your medication.

For more information about peripheral neuropathy, go to www.lymphomas.org.uk/PN

I told the consultant I could manage the symptoms, but he explained that because the lymphoma was present in both lungs, it wouldn't be very long before it would compromise my breathing and quality of life. I teach breathing techniques and could see the irony of this!

I started my first course of chemotherapy – R-CVP – on 1 July 2016. I was to have six courses given every three weeks. On the first occasion, I could feel I was having an allergic reaction to the rituximab, something that I had been warned could happen. My throat felt itchy, so the treatment was stopped and some anti-histamine was given. They then started rituximab again, but very slowly. I managed the treatment well and had no major reactions or infections after that.

Coping with hair loss

My hair was dyed red at the time and although I didn't lose it all, it went so thin that you could see my scalp. I hated the vision of red hair stuck to the bottom of the bath each day. My hair gradually grew back but was far darker than it used to be. I now embrace brown hair and definitely wouldn't return to red hair again – it's such a reminder of chemotherapy!

Coping with peripheral neuropathy

As a yoga teacher I am really aware of how my body feels.

After the second treatment I noticed I was losing feeling in my fingers and feet. I couldn't feel the base of my feet, which was affecting my balance.

I told my medical team about this before they started on the third round of treatment, so they removed the vincristine element of the regime. **I would urge anyone who notices any change in sensation to report it to their medical team immediately**.

As a result the neuropathy didn't get worse, but it was around six months before I started to get sensation back in those areas. In fact, it wasn't painful when it was numb, but as it was improving, I started to feel pain. This lasted for about 2-3 months. I would say it has returned to almost 100% now.

While my feet and fingers were affected by peripheral neuropathy, I did some self-massage, working on each toe and finger individually. I also found standing on the cold kitchen floor helpful.

Coping with work and the benefits of Floyd

Suddenly everything was changing. I teach various yoga classes including 'yoga for people living with cancer'. I decided from the start to be completely open with the groups and found that they were a massive support to me.

I wanted to keep teaching but knew that I needed to give my body the best opportunity to heal, so I stopped during chemo. Once treatment had finished I took on a much-reduced teaching load and am building it up again at my own pace. I'm gradually adding more workshops into the mix, choosing to do more of the classes I love.

I have a dog called Floyd, and was glad that I had a reason to get out of the house each day. Some days I felt so fatigued and wiped out, that all I could do was find a seat and throw a ball to Floyd. But on other days when I could take a walk, I found that exercise – and just being out of the house – was really helpful.

'I had a bit of a wobble. Maybe wobble is a bit understated. I had a complete meltdown!'

Treatment finished

I had a scan after my fifth treatment which showed I had a complete metabolic reaction to the treatment. I was thrilled, my family were thrilled and so were the medical team.

Now I had to look to the future and rebuild my life. I was struggling with fatigue, which would creep up on me and sometimes completely floor me. But I decided to accept it and just be kind to myself. As a result, I found I could manage the fatigue, and was just increasing the amount I did day by day.

It was the anniversary of my diagnosis recently, and I had a bit of a wobble. Maybe wobble is a bit understated. I had a complete meltdown! But thankfully it didn't last too long.

My fitness is really improving and I plan to take on a challenge soon, not only as a goal, but also as a way of continuing to push myself to achieve more physically.

Pam

#WhatMatters for Lymphatic Cancer Awareness Week 2017

A massive thank you to all our wonderful supporters – so many of you have been amazing, raising money, awareness and getting involved in other ways.

Only by continuing to work together can we make sure that no one has to face their lymphoma alone. All month you told us #WhatMatters and raised awareness and funds. We loved seeing all the different activities going on – from awareness stalls to some great fundraising events. We helped make more people lymphoma-aware than ever before. Thank you.

We are still putting together data from all the activity, but so far we know that:

We had over

44,000

visitors to our website during LCAW – an increase of 59% from 2016

On the 13 September alone, more than

8,000

people visited our website – the highest amount so far in 2017

Thanks to you sharing and responding to our social media posts – our social media reach was over

900,000

Almost

700

of you completed our #WhatMatters survey

We sent out

200

awareness, stall and purple party packs

For events in 2018, go to www.lymphomas.org.uk/fundraising-events


Getting involved with
the Lymphoma Association
#supportgrap
#WhatMatters

Based on a talk at our National Conference, Consultant Haematologist Professor Kristian Bowles explains **'What is lymphoma?'**

One size does not fit all

There is no simple answer to the question, 'What is lymphoma?' If you start by looking at the definition in the Oxford English Dictionary, it describes lymphoma as 'A tumour having a structure of the lymphatic gland.' But as a haematologist, this doesn't really mean a lot to me and I doubt that it is of much help to my patients either.

To me, lymphoma is a cancer that has developed from a type of white blood cell (in the case of lymphoma from a lymphoid cell). White blood cells are the cells of the immune system that protect us from infection. Therefore lymphoma can be thought of as 'cancer of the immune system'. Usually, lymphoma cells tend to collect and grow in lymph glands, which may be noticed by patients as swellings in the neck, under the arm or in the groin. Sometimes it can be in places we cannot feel, like in the chest and abdomen.

Swollen lymph glands are fairly common in everyday life and mainly occur in response to an infection like a cold. For that reason, GPs may suggest returning after about 3 weeks to see if the swollen glands have gone. It could be that the lymph nodes are swollen because they're doing what they should in fighting infection. If so, once the infection has gone, the glands go down. If the swelling persists, then further investigation may be considered.

Although usually a disease of lymph glands, it is not always the case that lymphoma occurs in lymph glands. It can affect any part of the body – the bone marrow, the spleen, the skin, the stomach, the eyes, the lungs – anywhere in fact.

Furthermore there are several different types of lymphoid cells and these can become cancerous at many different stages of cell development, giving rise to different subtypes of lymphoma. These can be very different in terms of symptoms, treatment and prognosis. Taken together this makes lymphoma not just one cancer. In fact, lymphoma is an umbrella term that describes a large group of related, but different diseases.

Classification of lymphoma

To understand how each subtype behaves and responds to treatment, lymphomas need to be classified. Classification of lymphoma began back in 1832 when Thomas Hodgkin wrote his description of a series of patients he saw who all had lymphoma. With developments in technology in the 20th century, doctors across the world were able to recognise that there were many types of lymphoma and a number of different classification systems were developed. In the 21st century we use a single system harmonised by the World Health Organisation (WHO) so that doctors across the planet have one way of classifying lymphoma.

Today the list of types of lymphomas in the WHO classification runs to over 60 different illnesses with different names that can sound, on the face of it, fairly similar, but these are distinct diseases and the subtype and the detail really matter.

It would be far too much to cover the diversity and complexities of all the different types of lymphoma in a single article. However, many lymphomas can be broadly thought of as being part of one of two groups – the high grade types or the low grade types. This can be useful when considering some of the general principles of lymphoma and its management, but would be insufficient to decide on treatment, for example, or to relate to an individual patient.

Differences between 'high-grade' and 'low-grade' lymphomas

With the **low-grade lymphomas**, the illness tends to develop over months or years and a person has usually had lymphoma for longer than those with high-grade disease at the point of diagnosis. In fact, in many people, the low-grade lymphoma is discovered entirely by chance; often the person didn't feel unwell at all.

Fifty years ago, you needed to be quite unwell to have a blood test or an X-ray or scan. Nowadays these tests are much more common and a chance finding of low-grade lymphoma is often the way this illness is diagnosed.

Some people may have a lump in the neck, but often a person may have been unwell with something entirely different. Symptoms of gallstones for example, and a scan followed by a biopsy, reveals an unexpected lymphoma.

As the low-grade types of lymphoma tend to grow more slowly and may not be causing any health problems, people are often managed with careful observation

('watch and wait'), which may take many years.

Studies have shown that if people aren't unwell then treatment can expose them to potentially unpleasant side effects of chemotherapy but without proven benefits in outcome. Whether this is the case with our newest drugs is still to be seen. As results from clinical trials in low-grade lymphomas can take as long as 10 or 20 years of follow-up to give us the answers it may be some time before we know.

Patients unwell with low-grade lymphoma need treatment, and these tend to be less intense than those used in the higher grade diseases. Most patients respond to treatment but despite this, low-grade non-Hodgkin lymphoma is presently a lifetime illness that runs a relapsing and remitting course.

The overarching treatment goal is to get the lymphoma under control so that there are no symptoms and for that therapy to provide as much time as possible before treatment is needed again. This can vary enormously, from a few weeks to many years and many lines of treatment may be given during the course of a patient's illness. Because **high-grade lymphomas (including most types of Hodgkin lymphoma)** tend to grow fairly quickly over weeks and months, people usually have symptoms that have taken them to the doctor. Treatment is always required for the high-grade lymphomas, generally with the aim of cure.

It is curious that the faster something is growing, the greater the chance of cure. The reason is that our DNA is very difficult to damage. It lives within a protective packaging and only comes out of its packaging when a cell needs to divide into two cells. It is at that point, as the cell is dividing, that the cell is particularly sensitive to chemotherapy. So, because high-grade lymphoma grows more rapidly, the DNA is unpackaged more often and therefore the lymphoma tends to be sensitive and often responds more quickly to chemotherapy.

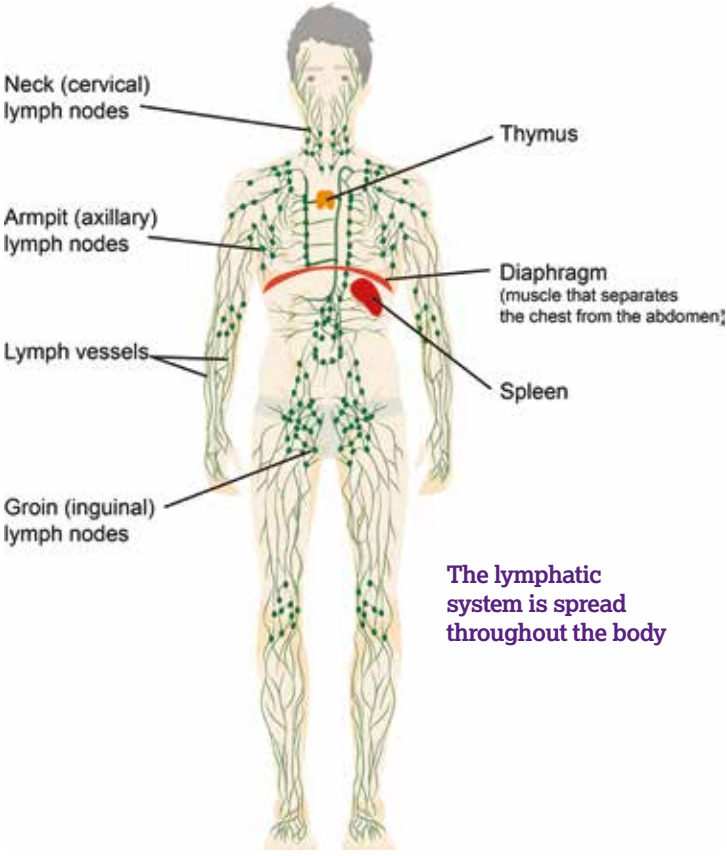
To cure high-grade lymphoma, however, often requires chemotherapy at the stronger end of the spectrum and treatment tends to be fairly intense with more side effects. Ultimately some patients, with treatment, can be cured of the high-grade lymphomas and some at present cannot. For a long time we felt that we only had one opportunity to cure these types of lymphoma, but we now recognise that, for an increasing number of patients, treatment can be given more than once with the intention of cure.

How we make a diagnosis and recommend treatment

To get a diagnosis of lymphoma, the patient needs to have a biopsy. Despite the common use of scans, it is still a biopsy that is the most important element in the diagnosis of lymphoma.

Simply stating that a person has lymphoma after the biopsy is insufficient. Far more information is needed for the medical team to make a full diagnosis and advise on a treatment plan and subsequent prognosis: Which subtype of lymphoma? What is the stage (where the lymphoma is in the body)? Is this the first time or relapsed disease? How large are the glands? How otherwise fit and well is the patient?

The diagnosis of the subtype of lymphoma is made by a pathologist who looks at the cell types, cell patterns and sometimes the genes in the biopsy sample. The stage is defined by the radiologist who reports the scans. Scans are very important and they provide essential information when considering treatment. Furthermore repeated scanning allows doctors to compare the progress of



The lymphatic system is spread throughout the body

the lymphoma treatment and determine whether the treatment response is satisfactory.

In my view, one of the most important things we have done in this country in the management of cancer in general over the last 20-30 years has been the introduction of the multidisciplinary team meeting or 'MDT'.

This is where all the component parts of the patient's experience – biopsy, scan, the meetings with the doctors and nurses in clinic – are considered together at the same time. At an MDT meeting a collection of doctors and nurses who are specialists in their fields discuss the patient's case. The doctors and nurses discuss the patient-specific factors, for example the symptoms, general levels of fitness, the patient's wishes and expectations; the radiologist will explain the findings of the scans; the pathologist will describe the findings of the biopsy and define the subtype of lymphoma.

In my view, one of the most important things we have done in this country in the management of cancer in general over the last 20-30 years has been the introduction of the multidisciplinary team meeting or 'MDT'.

At the end of the MDT a recommendation is made by the team of clinicians, nurses, pathologist, radiologist, and other healthcare professionals which is then discussed with the patient. It is by discussing all these aspects that the best course of treatment can be planned together with the patient.

The prognosis (outlook)

There are a number of prognostic markers, but they don't explain exactly what will happen to the individual. Everyone is unique. However when trying to gauge what is more or less likely to occur in the future, and specifically around questions about prognosis, factors to consider will include the subtype of lymphoma and how much lymphoma there is on the scans (the stage). It may also depend on the person's age, fitness, whether there are any other co-morbidities, blood results, the size of

the masses and whether they are confined to the lymph nodes or not.

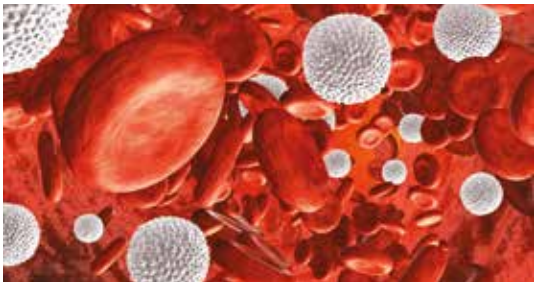
The future

We have come a long way in the last 200 years since Thomas Hodgkin wrote about his patients with lymphoma. Diagnosis has become more accurate and specific, scanning has been developed and integrated into routine care, management of patients is now a team effort and treatment is becoming more targeted and more effective. Consequently because of all this, outcomes for patients have improved.

However, more improvements are necessary and I look forward with a genuine sense of optimism to the future, towards treatments with better results combined with fewer and less severe side effects. I would like to think these new treatments will be increasingly developed in tablet form and more commonly given in the outpatient setting with fewer admissions to hospital and even better results. For many patients I see this future already here.

In summary?

Lymphoma is a cancer that affects the blood and exists in many subtypes. That means that for every person lymphoma is going to be something different. For the medical team it means that management needs to be tailored to the individual.



ask the experts

Should I have a flu jab?

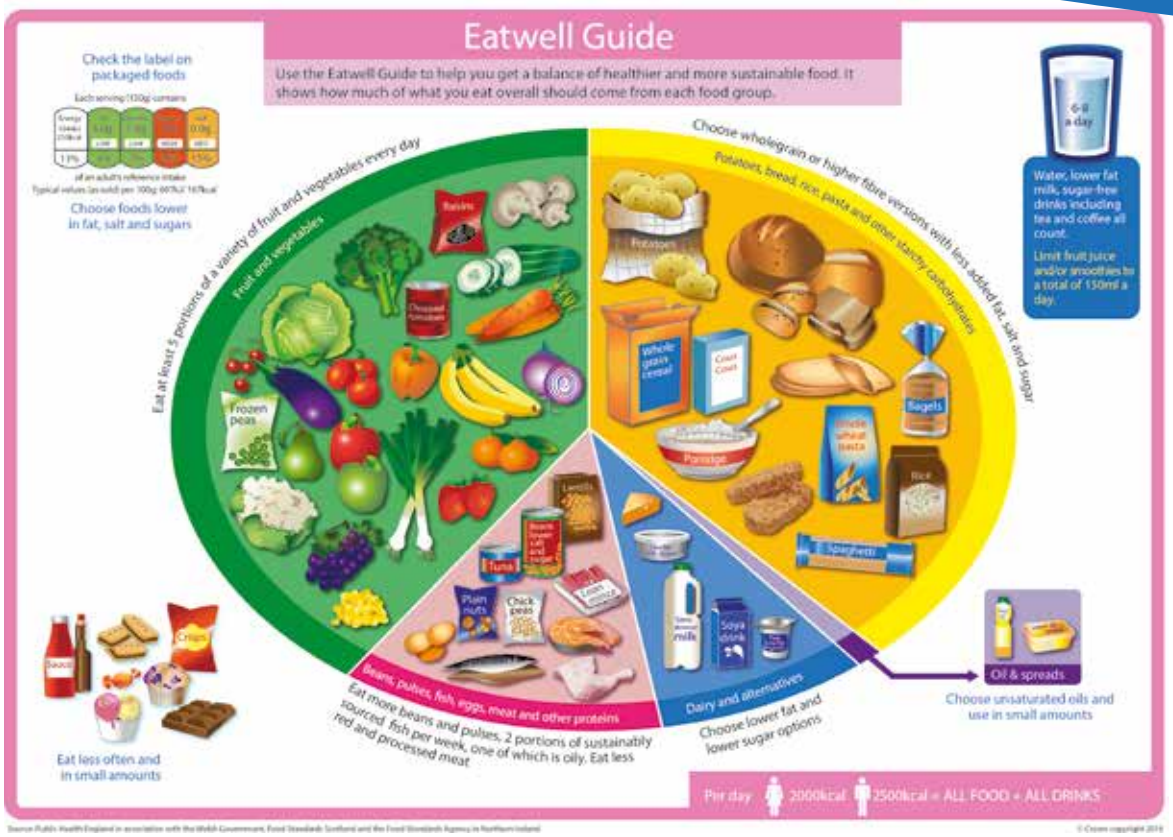
You are recommended to have an annual influenza vaccine or 'flu jab' if you have lymphoma, if you have had your spleen removed (splenectomy), if you are having chemotherapy, steroids or radiotherapy. These can suppress your immune system, making you more vulnerable to flu. People who are in close contact with you should also have the flu jab.

The timing of the flu jab is important. Ideally people should have this before they start treatment because once on treatments such as rituximab, there is evidence to suggest the flu vaccine is not as effective.

New vaccine is available based on the strains experts think will be most likely to be around in the coming year, so you need to be vaccinated every year. If you are attending hospital regularly for treatment it is likely you can have your flu jab there; otherwise ask your GP for advice on where and when to have the jab.The flu vaccine does not contain live virus, so you cannot catch flu from having the jab.

Important advice:

- ✓ **Aim to have the flu vaccination before you commence treatment.**
- ✓ **If on treatment, ask your doctor about the best time to have the vaccination.**
- ✓ **For people who have had a transplant; you should receive the flu vaccination 6 months post-transplant and annually thereafter.**



Can you give some guidance on diet, nutrition and your view on alcohol during and after treatment?

We know patients can be very poorly and may lose their appetite during treatment. This is definitely not a time to try to lose weight; instead, ensure you have enough calories to maintain your weight. After treatment has finished, some people struggle to lose weight which, together with a loss of energy and other changes to the body can be difficult. The Eatwell Guide (pictured above) provides guidance on a balanced diet, which is important for everyone. There is no evidence that supplements make a difference.

During treatment, people's taste may change, often putting them off alcohol. There is no reason not to drink alcohol if you have lymphoma, so long as you keep it in moderation. If you do drink, stick within recommended guidelines. GOV.UK suggests that both men and women drink no more than 14 units of alcohol each week, over three days or more. This is the equivalent to six pints of average strength beer or just under six standard glasses of wine per week. However, we often hear that people go off the taste of alcohol, even before they are diagnosed with lymphoma.

The Eatwell Guide can be viewed at GOV.UK

With thanks to Dr Cathy Burton, Consultant Haematologist at Leeds Teaching Hospitals and Dr Graham Collins, Consultant Haematologist, Oxford Cancer and Haematology Centre for answering these questions.

Having lymphoma didn't stop me being a mum

My daughter Tilly had just turned seven when I was diagnosed with anaplastic large T-cell lymphoma in March 2016.

My husband Frazer and I had hoped to be able to get help to explain my cancer to her, but in the end it happened in a far less planned way. Frazer was picking Tilly up from school as I was in hospital, and some of the mums in the playground asked how I was doing. Having told them about the diagnosis, we both realised we had to tell our daughter now in case she heard about it from someone else.

So rather than the a formal talk, I sat on the bathroom floor with her and explained about my lymphoma. I told her what we knew, that the treatment would make me very poorly, that the strong medicine would make my hair fall out, but that the kind of cancer I had was very treatable and the doctors were working hard to make me better. We found a couple of books really helpful, *Nowhere Hair* and the *Secret C*, and used these as a way to let her talk openly about what was happening. I think it really helped her articulate, for example, how angry she was.

My illness had come on quickly at the beginning of the year. I was so exhausted, I was having to drag myself to school to pick Tilly up. I also had a cough that wouldn't go away, a persistently high temperature, swollen lymph nodes and night sweats. I was also out of breath.

My illness had come on quickly at the beginning of the year. I was so exhausted, I was having to drag myself to school to pick Tilly up.

I booked into the GP for a health check. I was 46 and thought they would just tell me these were symptoms of menopause. The GP thought I may have been sitting awkwardly at work and suggested a workplace assessment, but also referred me for a chest X-ray and blood tests.

Before the results of the chest X-ray were available I was rushed into A&E as the tightness in my chest got worse and I felt really ill. The hospital doctors suspected lymphoma and carried out a biopsy from a swollen lymph node in my neck. After a terrible waiting game, where the fluid on my lungs got so bad I had to have a chest drain, I was diagnosed with anaplastic large T-cell lymphoma. The consultant haematologist wanted to start chemotherapy straight away with six courses of CHOP chemotherapy every 21 days. I was ALK-negative and it was planned that chemotherapy would be followed by a stem cell transplant using my own stem cells.

I ended up in hospital after each cycle. I had infections and neutropenia and, when I wasn't in isolation, having to visit me on a hospital ward was difficult for Tilly. We explained how people are in hospital because they are ill, but still had to make sure she was quiet and well behaved, so that she didn't disturb the other people. We were always made to feel she was welcome and the nurses would spoil her with biscuits! It was important to me that we still spent time together, so we would do colouring books and play games like travel Scrabble.

Once I was home, if I couldn't do much, it was still nice to snuggle up and share books together, or sit with her and help her craft or play with Lego. One thing I was determined not to miss out on was school sports day and I made sure I entered the mothers' race. I thought the other mums would let me win, but they didn't! But it was great to be able to participate and show Tilly that I was still her mum.

The stem cell transplant meant that I was away from home for at least three weeks. Before treatment started we took Tilly to Build-A-Bear and she chose a teddy with a recording of my voice saying goodnight to her for when I was away from home. In fact I was away from home for a long time, initially in ambulatory care, receiving high dose LEAM chemotherapy, and then in hospital once my neutrophils became very low and the side effects too bad. While I was in ambulatory care, we went out for walks and visited museums together as a family. It was quite surreal to be doing that with the chemotherapy attached to me, and of course I didn't go back home with Tilly and Frazer.

Did you know?

We have a storybook for children entitled *Tom has lymphoma* which you might find helpful when talking to your child.

I thought the other mums would let me win, but they didn't!

Frazer has his own business a 2-hour commute away. During my treatment, he didn't want to be too far away from home and, thanks to the support of his colleagues, was able to adapt things. Not only did he have to adjust working patterns, but had to get to grips with lunch boxes, school uniform, after school clubs and cooking - although he was already a good cook! Friends were also brilliant and put together a rota to pick Tilly up from school and give her play dates.

When I knew I would be having a stem cell transplant, I did a manual for Frazer. It felt important to me to still be involved - some might say I am a control freak! I wanted to pass on little things - like what her favourite breakfast is, when her friends' birthdays were. I wanted life to be as normal as possible. But some things that I would never have allowed started creeping in, like chocolate in the lunch box, hair washed less often, toe nails uncut. Throughout treatment it felt important for us both to take her lead. So, for example, when I was away from home having the stem cell transplant, she didn't want to Skype or Facetime as she found it too upsetting. I sent her little postcards and text messages instead.

I think the normality of school was really helpful for Tilly. The teachers and home link workers were aware of the situation, and allowed her to take days off to visit me and to bring in her teddy if she needed to. It was quite low key generally, but I know they would have supported us if we had needed any additional help.

I knew I would lose my hair and eyebrows and we talked about this. Initially Tilly said she wouldn't speak to me if I had no hair. When my hair began to fall out, I told her she could cut it for me. Tilly thought this was great fun and something she loved doing. Once it was really thin, I let her use Frazer's electric razor to remove the rest of it. Involving her in this really seemed to help and as my hair was growing back, she liked stroking it – I suppose we all found a new normal.

When I came home from hospital, I was still very ill and fatigued easily. I couldn't do very much, which really wasn't like me. I love having Tilly's friends to play, but that wasn't possible for a while, as I was so susceptible to infections. I am nearly a year post stem cell transplant, and I am back to work and, although I work from home most of the week, the one day I spend in London is really exhausting.

Cancer has changed our family. But being a mother of a young child has really helped my recovery. She gives me a reason to get up in the morning. She makes me laugh every day. The stem cell transplant is a tough treatment but I am so grateful that I've got more of a chance of seeing her grow up.'

Katherine

More about anaplastic large T-cell lymphoma (ALCL)

ALCL can be ALK-postive or ALK-negative ALCL, depending on whether a protein called 'anaplastic large-cell kinase' (ALK) is present.

ALK-postive ALCL often affects people under 35. ALK-negative ALCL often affects older adults aged 40-65. Both types are more common in men.

Most people have CHOP chemotherapy, but treatment depends on several factors such as your age, stage of lymphoma and its ALK status. Some people might have more intensive chemotherapy or a stem cell transplant after chemotherapy.

Do you fancy seeing the autumn colours... *from the air?*

If you have ever wanted to do a parachute jump here's your chance! We're looking for adventurous volunteers to do a fundraising parachute jump and if you raise enough in sponsorship you will get to jump for free! With airfields across the UK, it couldn't be easier.

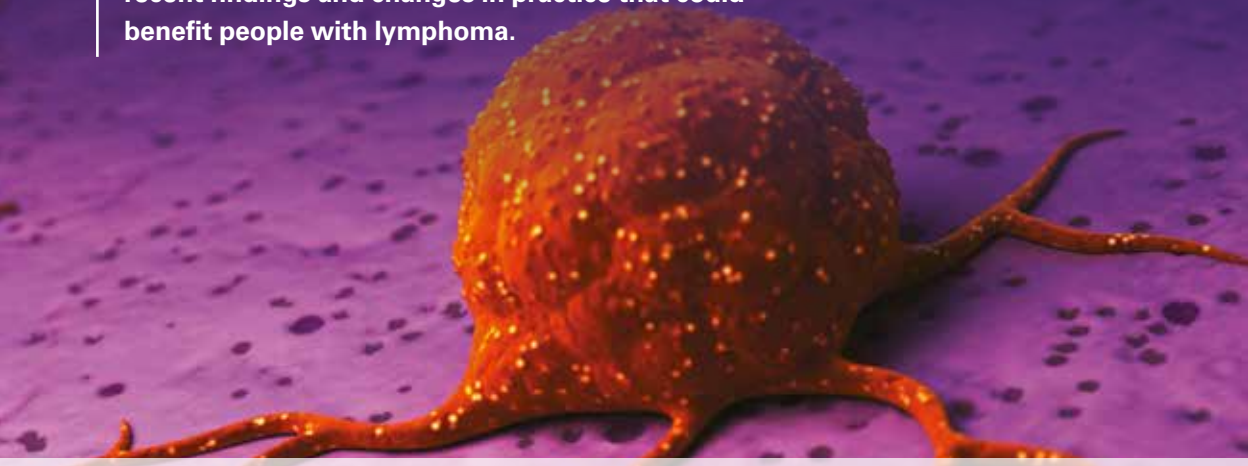
If you'd like to make a thrilling skydive from 10,000 feet, **give us a call on 01296 619419** or enquire using our website. We will send you a full information pack and everything you need to take part in the experience of a lifetime.

Alternatively you might like to organise your own adventures in the sky…
Sisters Sue and Jan (above) wing-walked in aid of the Lymphoma Association. Jan was used to doing challenges, but mainly on the ground, so when Sue suggested a wing-walk, she was more than a little apprehensive. Sue explains: 'I wanted to take on a challenge because last year my husband Phil was diagnosed with mantle cell lymphoma. He went through six courses of Maxi-CHOP and BEAM chemotherapy followed by a stem cell transplant. Phil is now 12 months into remission so I wanted to raise money for the Lymphoma Association. The information we were given in the hospital was invaluable in understanding the disease and helping me as a carer.'

Watch Sue and Jan's video at www.youtube.com/LymphomaWingWalk

Update from the 14th International Conference on Malignant Lymphoma (ICML)

ICML is arguably the most significant lymphoma meeting in the world, gathering experts to discuss recent findings and changes in practice that could benefit people with lymphoma.



Biology of lymphoma: As well as testing new treatments, clinical trials collect samples that can be used for other studies to help advance our understanding of lymphoma. There are more questions than answers at the moment, but the hope is that our understanding of the biology of lymphoma will help identify which treatments are best for which person.

Hodgkin lymphoma

Most people with Hodgkin lymphoma are cured with standard ABVD chemotherapy. Evidence is emerging that the amount of chemotherapy or radiotherapy can be reduced for people who respond well on an interim (part-way through treatment) PET scan, reducing side effects. Earlier this year, brentuximab vedotin was recommended for some people with Hodgkin lymphoma that has relapsed (come back) or was refractory (didn't respond) to treatment. Initial results from a large phase 3 trial replacing bleomycin ('B' in ABVD) with brentuximab vedotin suggest

that this combination may give slightly better outcomes than standard ABVD as a first-line treatment.

Checkpoint inhibitors have impressive results in clinical trials for difficult-to-treat Hodgkin lymphoma. They work by helping the immune system recognise and attack the lymphoma. One of these drugs, nivolumab, was recently approved for relapsed or refractory classical Hodgkin lymphoma. The availability of checkpoint inhibitors together with brentuximab vedotin should allow more people to go into remission (no evidence of lymphoma) so they can have a potentially curative stem cell transplant. They also give other options to people unable to have a stem cell transplant.

Chronic lymphocytic leukaemia (CLL)

New drugs are big news for CLL – they are prolonging survival, providing chemotherapy-free treatment options and even offering the potential of a cure. The targeted treatment ibrutinib is in routine use and there is now information about how people are doing on this drug outside of a clinical trial when there are not such strict criteria for who can have it. Ibrutinib can keep CLL under control for years, even for people with certain genetic changes (17p/11q deletions) that make CLL difficult-to-treat or who have had several relapses. Reducing the dose if needed seems to give better outcomes than taking a break from treatment. Ibrutinib is not usually curative and the lymphoma is likely to get worse at some point during treatment. The approval of another new drug, venetoclax, offers another option for people who are no longer responding to ibrutinib.

Treatments for CLL and other types of low-grade (slow-growing) lymphoma commonly leave small amounts of lymphoma behind – 'minimal residual disease (MRD)' – which can cause relapse. New treatment combinations are increasing MRD negativity rates – where there is no disease left behind. Many treatments have to be taken long-term to keep lymphoma under control. People who are MRD negative may be cured and able to stop treatment.

Combinations being investigated for CLL include:

- bendamustine chemotherapy to reduce CLL followed by a combination of obinutuzumab (a newer CD20 antibody, like rituximab) and venetoclax
- ublituximab and ibrutinib.

Newer drugs can bring problems as well as solutions. In the ongoing RIAltO trial, some people were originally given the targeted drug idelalisib or placebo (a dummy drug) together with other obinutuzumab and chemotherapy as a first treatment. People who had idelalisib had many more serious side effects than those who had placebo. RIAltO is continuing without idelalisib. Idelalisib has much less toxicity when used for people who have already had other treatments that weakened their immune systems.

Follicular lymphoma

Average survival for people with follicular lymphoma is now approaching 20 years and it is important to balance the need for treatment with the risk of side effects. For example, radiotherapy alone has few side effects and can be very effective if the lymphoma is in one

EZH2 mutations predict response to an EZHT inhibitor

Tazemetostat is a type of cell signal blocker called an EZH2 histone methyl transferase (HMT) inhibitor. It targets and blocks a protein that encourages lymphoma cells to divide and multiply. Blocking this protein may help to stop lymphoma from growing.

In an ongoing study, people with follicular lymphoma and diffuse large B-cell lymphoma who had mutations (changes) in EZH2 had a much higher response rate to tazemetostat. If it can be done routinely, testing lymphoma cells for certain mutations could help doctors make decisions about treatment.

Research is continually improving our understanding of lymphoma and improving outcomes.

place or a few places close together. Although adding chemotherapy reduces the risk of relapse, it increases side effects and doesn't increase overall survival.

Maintenance rituximab is used routinely for follicular lymphoma but the need for this should also be considered for every person. It can cause side effects and doesn't affect overall survival but rituximab might reduce the risk of transformation – where follicular lymphoma changes into a more aggressive (faster-growing) form.

Several chemo-immuno-therapy regimens (chemotherapy with antibody therapy) are effective for advanced-stage follicular lymphoma. Newer antibodies like obinutuzumab may offer more effective alternatives to rituximab. In future, the R^2 regimen (lenalidomide and rituximab) might be a chemotherapy-free first treatment option if the results of a forthcoming large trial show this combination is better and less toxic than chemo-immunotherapy. For relapsed and refractory follicular lymphoma, there are encouraging results from trials of newer drugs, including tazemetostat, copanlisib, duvelisib and pembrolizumab.

Mantle cell lymphoma

Long term follow-up of the pivotal study comparing ibrutinib with temsirolimus showed that the benefits of ibrutinib were maintained long term. However, using it early, such as in first relapse, gave a higher response rate and longer remission. Other studies are looking at how best to use ibrutinib for different circumstances, such as with chemotherapy as a first-line treatment for older people. Several studies are now looking at the combination of ibrutinib and venetoclax, with good initial response rates and importantly, MRD negative results, which could reduce the risk of relapse. Further evidence was also presented that rituximab maintenance can prolong remissions. For people who are fit enough, rituximab maintenance after a stem cell transplant as first-line treatment clearly improves outcomes.

Diffuse large B-cell lymphoma (DLBCL)

First-line chemo-immunotherapy for DLBCL can often cure lymphoma. Trial results suggest people with a negative PET scan (no active lymphoma) at the end of treatment for DLBCL could be spared the long-term effects of radiotherapy as they have a similar outcome whether or not they are given radiotherapy.

Some factors make DLBCL more difficult to treat. For example the 'ABC' subtype, which can be detected through tests on the lymphoma cells, is reported to have a worse prognosis (outlook) than the 'GCB' subtype. Research is also trying to improve outcomes for people with double-hit DLBCL, where the lymphoma cells have two major genetic changes and often behave more aggressively. Combinations including lenalidomide and ibrutinib might offer effective alternatives to standard chemo-immunotherapy in ABC DLBCL. Other first-line treatments tested so far, including substituting obinutuzumab for rituximab or using other more intensive chemotherapy regimens like DA-EPOCH, have not improved on standard treatment.

Combinations of newer drugs could improve outcomes

Relapsed or refractory DLBCL is difficult to treat. A new drug, polatuzumab vedotin, was recently granted PRIME (PRIority MEdicine) status by the European Medicines Agency (EMA), meaning it is on a fast-track to approval following impressive results in a phase 2 trial. This drug is in trials with other treatments for first-line treatment and relapsed and refractory disease with very encouraging early results.

T-cell lymphoma

CHOP chemotherapy has been the standard treatment for T-cell lymphoma for many years but many people do not respond well. Unfortunately trials have been unable to identify a chemotherapy regimen that gives better outcomes. New trials are focusing on adding new drugs to CHOP, eg romidepsin. The exception to this is extranodal NK/T-cell lymphoma where new regimens including asparginase, eg SMILE, have improved outcomes.

The role of a stem cell transplant in prolonging remissions is still uncertain and a clinical trial is needed to answer this question.

CNS lymphoma

Only certain drugs can cross the blood-brain barrier (which protects the brain), limiting the treatment options for primary central nervous system (CNS) lymphoma (PCNSL). The MATRix regimen of chemotherapy and antibody therapy is effective and has now become standard treatment and recent trial results suggest autologous stem cell transplant (ASCT) is as effective as whole brain radiotherapy in reducing the risk of relapse but with less effect on brain function. The combination of MATRIX and ASCT has significantly improved outcomes for people who are fit enough for such treatment. Studies are investigating whether there are any factors that can be used to identify people at high risk before they relapse. New treatments for relapsed PCNSL are in clinical trials, including new chemotherapy regimens and targeted drugs including ibrutinib and nivolumab.

The future – CAR-T cells and other immunotherapies

Cell signal blockers like ibrutinib, idelalisib and venetoclax have been a focus of attention in recent years. These drugs have transformed the outcome of people with low-grade lymphomas but are generally not curative and are very expensive.

The current focus is on immunotherapy – drugs that harness the power of the immune system. Checkpoint inhibitors have promising activity in difficult-to-treat types of lymphoma, as do antibody-drug conjugates like polatuzumab vedotin. Early results with a new type of treatment, CAR-T cells, are causing great interest for several types of lymphoma. CAR-T cells are your own T-cells, collected and genetically modified (changed) to recognise and kill lymphoma cells that have a certain protein on their surface. The genetically modified T cells (CAR-T cells) are grown in the laboratory until there are enough of them, then given back to you, like a blood transfusion. CAR-T cells using donor cells are also in development. Initial results from trials in relapsed or refractory DLBCL are very encouraging.

These drugs are in the early stages of development and unleashing the immune system can cause very serious side effects. However, there is hope that this treatment could be curative with some people who have failed many different types of treatment going into complete remission after CAR-T cell treatment.

Stem cell transplants in the era of targeted drugs

New drugs are big news for lymphoma so there is much debate over when to use stem cell transplants, which can still give a chance of cure for many people with lymphoma. Many new drugs give good response rates but the responses are not always long-lasting or you have to keep taking the drug. For some types of lymphoma, new drugs can be used to put the lymphoma into remission so that a stem cell transplant can be given. Research continues into how best stem cell transplants and newer drugs can be used to improve outcomes.

With thanks to Dr Robert Marcus, Consultant Haematologist, for reviewing this article.

Find out more

Find out more about clinical trials at Lymphoma TrialsLink at www.lymphomas.org.uk/LMTrialsLink

Two very different challenges

‘Many reading this will be familiar with the emotional and physical challenge of lymphoma’ Pete

I was diagnosed with Hodgkin lymphoma in 2009 and quickly realised that to become better I had no option but to set myself on the tramlines laid out for me – the tests, the treatment, the consequences of the medicine, the joys of remission and the very surprising emptiness that followed.

Perhaps, as a result of these feelings, last January I set myself a challenge of my own choice.

I had really appreciated the support of the Lymphoma Association, the ease with which they answered the phone, the kind and considered voices I spoke to and of course my invaluable ‘buddy’. Here was an organisation that has a humanity, just like the very best of the nurses I met in hospital; the ones who took time to hold my hand.

During the eight years of my association with the charity, I was drawn to their fundraising events, and particularly ‘the ‘Arctic Challenge’. Each year the idea of this became more

I woke to bright whiteness and trees bending under the sheer weight of the fresh snow. I also woke to the sound of 70 noisy and excited Huskies. I was about to start the Arctic Challenge – 200 kilometres of dog sledding in five days through the most beautiful place I had ever seen.

compelling. Following a work night out, I sat and read the invite in the magazine for the umpteenth time. It was 2.30am and armed with an iPad and a glass of Jack Daniels, I pressed the 'submit' button. I was on the way.

The first thing to think about was the fundraising, and by setting an ambitious target my activities had a focus. With help and ideas from family and friends, we held lots of activities and events that year: a summer Band 'n' Barbeque at my college, the sale of some paintings I had managed to finish, a matched donation from a bank, a 'just giving' page and a Christmas raffle.

A much more strenuous activity was the training. I had received a rather heavy training schedule from the organisers, which I took seriously. I joined a fitness group, which I enjoyed each week. I also joined a gym, which I did not enjoy. I stuck with the schedule, disturbed only by the occasional virus. Like most people in remission, viruses are a real nuisance and mine usually take 4-5 weeks to get rid of!

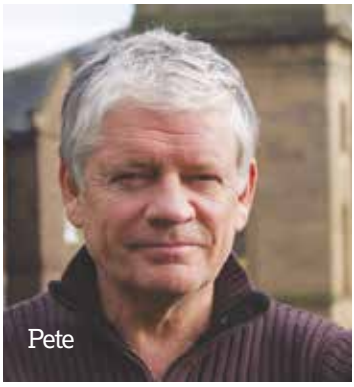
The third and final aspect of preparation was the kit list – it was huge and initially seemed almost unachievable. At least that year family and friends were able to find an easy solution to Christmas, father's day and birthday gifts. I had a steady stream of waterproofs, jackets, gloves, head torches, thermals, balaclavas and hats. I was ready!

After a tearful goodbye to my lovely wife, I arrived at Heathrow and met 11 other 'Arctically Challenged' strangers, all of whom had their own stories. The flight to Stockholm took just two hours, followed by a transfer to Kiruna in the north of Sweden, inside the Arctic Circle.

In hospital, especially at the worst times, I had suffered the visit of an unwelcome visitor. I called him my 'alien' and he made many night-time visits during the early days of diagnosis and treatment. He never had anything positive to say and kept jibing and pestering me. After my last treatment I thought I would never hear from him again. But as the plane descended and the views of frozen mountains, roads, lakes and forests appeared, he came back! This evil stowaway was in my rucksack saying: 'What have you done? You have no idea what you have let yourself in for!'

He was right! Through all the preparation I had never thought about being in the Arctic. The clue was in the title, but somehow I had managed to avoid addressing the obvious.

I woke to bright whiteness and trees bending under the sheer weight of the fresh snow. I also woke to the sound of 70 noisy and excited Huskies. I was about to start the Arctic Challenge – 200 kilometres of dog sledding in five days,



Pete

through the most beautiful place I had ever seen. I was so far out of my comfort zone that I could barely function. On the pretence of needing a different sized hat, I met one of the leaders and explained how I felt. She was really kind and arranged for me to be in her team. Just like the nurse in hospital, her kind words and support essentially served to hold my hand.

The days that followed were unforgettable. Learning to drive the Huskies took far more skill than I would have imagined, but we all learned quickly. Following the leader, we set off at some speed, such that it was difficult to cling on. At our first turn, there was a ditch and a downhill slope. Surprisingly, I stayed upright and mobile, but behind me carnage ensured. The next sledder had fallen, creating havoc behind her as her Huskies had sped away. Within the first hour, there were several such incidents and we still had 199 kilometres to go! The concentration needed was intense and any lapse was sure to leave you upside down and stuck in a snowdrift. Slowly the accidents became less frequent and the group began to appreciate the joy of this challenge and the magical scenery we were surrounded by. I was beginning to think my 'alien' had been wrong.

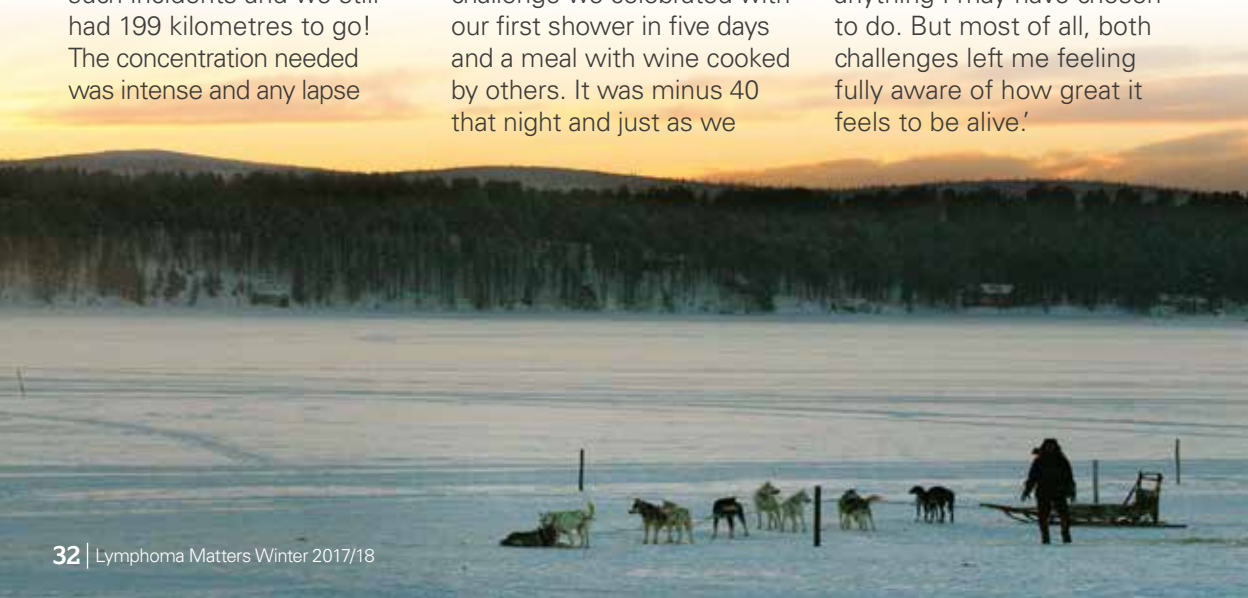
After sledding down hills, struggling to help the dogs up hills, over frozen lakes and through white frosted forests, we reached a wilderness camp as twilight was falling at 4pm. We were exhausted. We now realised what the training was really for, because for the next five hours we had to house the dogs, chop wood, prepare dog food, feed 70 hungry Huskies, fetch and boil water and prepare a meal that we finally managed to sit down to at 9pm.

Over those five days friendships were made, talents and stories shared and the relationship between rider and dog team evolved. On the fifth day as we finished the challenge we celebrated with our first shower in five days and a meal with wine cooked by others. It was minus 40 that night and just as we were about to settle for the night, the Northern Lights provided us with an amazing display of green and yellow. We were spellbound for nearly two hours.

Just like my experience of lymphoma, the Arctic Challenge left vivid images, memories, new relationships and a feeling of achievement being involved in something that was far removed from anything I may have chosen to do. But most of all, both challenges left me feeling fully aware of how great it feels to be alive.'

About Hodgkin lymphoma

Nearly 2,000 people are diagnosed with Hodgkin lymphoma in the UK each year. While Hodgkin lymphoma can affect people of all ages, it is most common in people aged between 15 and 34 and over 60. To find out more about Hodgkin lymphoma go to www.lymphomas.org.uk/HL



£70
could help train and support a lymphoma buddy for a year

£25
could help cover the cost of running a support group for a month

£50
could help fund two bursary places at our National Lymphoma Day for patients and carers

It costs around
£5
to answer a helpline phone call

It costs around
£10
to produce every lymphoma information pack that we send out

Get into the *Christmas* spirit

With Christmas fast approaching, we have lots of festive fundraising ideas to help spread some Christmas cheer and make a difference. To find out more about how you can get involved go to www.lymphomas.org.uk/christmas.

Order a pack

Order your festive fundraising pack, which has all you need to have some festive fun and raise vital funds and awareness. Ideas include:

- Christmas crafting
- Inviting your friends round for a Christmas coffee morning
- Adding some merry cheer with our Christmas quiz
- Showing off your best/worst Christmas jumper
- Taking part in a Santa dash or winter ramble.

Gifts

Treat someone special to a Lymphoma Association Donation Voucher – perfect for the person who is tricky to buy for!

Christmas cards

Don't forget to order your cards, buy online or by calling us on 01296 619400 for an order form.

For information about all our festive fundraising check out www.lymphomas.org.uk/christmas, contact the fundraising team on 01296 619400 or email fundraising@lymphomas.org.uk.

Lymphoma Association Support Groups near you

Aylesbury
Bangor
Bath
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)
Wigan
Lymphoma Association Support North West (closed Facebook support group)
Lymphoma Association Support South West (closed Facebook support group)

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.

Support groups tell us what matters during Lymphatic Cancer Awareness Week.

Tell us #WhatMatters

A big thank you to all those who got involved in our Lymphatic Cancer Awareness campaign where people told us what matters to them, raised awareness and helped raising funds. See pages 14-15 to read more about the week.

New Support Group Wales

A new Support Group launched in Mold at the beginning of October. It will meet at Flintshire Local Voluntary Council on the first Friday of alternate months from 2-3.30pm and has the full support of the Clinical Nurse Specialist teams at Glan Clwyd and Wrexham Maelor. To find out more about the new Mold group, or any of our Support Groups around the UK, go to www.lymphomas.org.uk/SupportGroups or call our Freephone helpline on 0808 808 5555.

Have you received a lymphoma diagnosis and want to use your experiences to help others? Have you got an interest or experience in facilitating workshops? We are looking for volunteers to run our *Live your Life workshops* across the country. Call our co-ordinator Rachel on 01296 619434 or visit **www.lymphomas.org.uk/lylvolunteer**

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

Events

for people affected by lymphoma

for healthcare professionals

Events for people affected by lymphoma

Live your life events

Bath, Friday 20 October
Frimley, Thursday 26 October
Nottingham, Thursday 16 November
London, Friday 24 November
Norwich, Thursday 7 December

Working after cancer workshops

London, Tuesday 7 November

Find out more:
www.lymphomas.org.uk/live-your-life
01296 619434
liveyourlife@lymphomas.org.uk

Know your lymphoma conferences

Belfast, Saturday 4 November
Hull, Saturday 2 December

National conference

Manchester, Saturday 12 May 2018

Find out more:
www.lymphomas.org.uk/laconferences
01296 619412
conferences@lymphomas.org.uk

Education and training for healthcare professionals

Focus on lymphoma study day

Cardiff, Friday 17 November

Ideal for staff new to haemato-oncology or as a comprehensive lymphoma refresher for more experienced staff.

South central lymphoma forum

Basingstoke, Wednesday 22 November

This evening meeting will include networking and lectures from keynote speakers Professor Peter Johnson (Southampton) and Dr Kate Cwynarski (London)

Lymphoma management

Keble College Oxford, 25-26 June 2018

This intensive 2 day course for medics, CNSs and ANPs provides a comprehensive overview of the diagnosis, treatment and management of lymphomas. Endorsed by BSH and accredited by RCPath for 12 CPD study hours.

Find out more:
www.lymphomas.org.uk/hpconferences
01296 619412
conferences@lymphomas.org.uk

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

Booking is open for our 2018 National Conference Saturday 12 May, Manchester.

Book your place now to get our earlybird rate of £25.

See the inside back cover for more information on our upcoming events.

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www.lymphomas.org.uk
Freephone helpline 0808 808 5555

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

If you would like to make a donation towards our work please:

- Visit www.lymphomas.org.uk/donate
- Text LAUK02 and the amount you'd like to donate, eg LAUK02 £5, to 70070
- Call us on 01296 619419.

Lymphoma association