

# lymphoma

## MATTERS

ISSUE 106 | WINTER 2016

Should I  
seek a  
second  
opinion?

LATEST NEWS

PERSONAL  
EXPERIENCES

FOCUS

Treatment  
considerations  
as we get older



Lymphoma  
association

# 13 Fundraising



# 14 Lord Campbell



# 8 Treatment considerations as we get older



# 24 Drug development



# 32 Support groups

# Contents

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: Read Victoria's story on page 22  
Editor: Anne Hook

# 04 News and updates

Latest news and developments

# 18 Should I seek a second opinion?

When is seeking a second opinion helpful?

# 20 Asking the expert

Flu, pneumonia and shingles jabs

# 27 Update on T-cell lymphomas

What's new in treatment for T-cell lymphomas

# 28 Ron's experience

The challenges of relapsing lymphoma

# 30 Support group update

What's happening in your area?



Read the latest news and views on our **Lymphoma Matters blog** at [www.lymphomas.org.uk/LMBlog](http://www.lymphomas.org.uk/LMBlog)





Jonathan Pearce  
Chief Executive

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

## Campaign launched for national lymphoma data audit.



We hope you like our magazine. We'd love to hear your comments at [publications@lymphomas.org.uk](mailto:publications@lymphomas.org.uk)

# Making it personal

We've recently launched a campaign for a national lymphoma data audit to improve lymphoma data collection and, in turn, treatment and outcomes for lymphoma.

Data isn't always seen as the most interesting subject. Yet accurate, reliable data is important, particularly for cancer, where detailed information on diagnoses, treatments and outcomes is crucial for better understanding of how services are planned.

UK cancer data is typically collected from hospital and laboratory systems and processed by a network of cancer registries. It's a complex system and, inevitably, there are challenges in ensuring data is complete, consistent and accurate. For lymphoma, the situation is compounded by its complexity with more than 60 subtypes.

When hospitals make lymphoma diagnoses and prescribe treatments, the data sent to the regional cancer registries isn't always accurate or complete. Often it lacks details of the particular lymphoma subtype – crucial to understanding diagnosis, treatment and outcomes. As a result, the data held centrally on lymphoma – in England, at the National Cancer Registration and Analysis Service – is of much poorer quality than what's available for many other forms of cancer. Generally, data are only available on Hodgkin and non-Hodgkin lymphoma, masking a range of important variances and differences.

Better data by lymphoma subtype will help us understand and deliver improvements in patient diagnosis, treatment, care and outcomes, so that the UK services can match the best healthcare in Europe and across the world.

For more information on the campaign and how you can support it, go to [www.lymphomas.org.uk/Audit](http://www.lymphomas.org.uk/Audit).



# £318,000 Big Lottery grant to help fund wellbeing project

The Lymphoma Association's new education and support programme, *Live your Life – living with and beyond lymphoma*, is set to be launched this autumn thanks to a £318,000 Big Lottery grant. The grant is in addition to the £9,500 we raised through a fundraising appeal earlier this year.

The grant will enable us to deliver lymphoma-specific courses designed to help people get back on their feet once their treatment has finished. Topics will include: diet and exercise, coping with anxiety and stress, mindfulness, finances, getting back to work and recognising symptoms of recurrence.

Courses will be delivered in hospitals and cancer centres by someone with experience of lymphoma, together with a health professional. They will take place at local volunteer

support groups and on our website through a series of videos and information pages.

## Extremely grateful

Stephen Scowcroft, our head of business development said: 'We're extremely grateful to the Big Lottery Fund and those who donated to the *Live your Life* fundraising appeal. This tailored, lymphoma-specific wellbeing programme has been designed to empower people to improve their quality of life.'

## New patron for Lymphoma Association

We are delighted to welcome Lord Menzies Campbell, Olympian and former leader of the Liberal Democrats, as our new patron. Lord Campbell was diagnosed with non-Hodgkin lymphoma in 2002 and has been in remission for 13½ years.

.....  
**Read his full story on pages 14-17.**

## Thousands surviving decades after cancer

**A report published by Macmillan Cancer Support has revealed more than 170,000 people are living with cancer in the UK who were diagnosed in the 1970s and 1980s.**

The *Cancer: Then and Now* report draws upon research conducted by Macmillan Cancer Support and the National Cancer Registration and Analysis Service (NCRAS).

The report, which compares the diagnosis, treatment and care of cancer in the 1970s/80s to the 2010s also reveals that people, on average, are twice as likely to survive at least 10 years after being diagnosed with cancer as they were at the start of the 1970s.

Jonathan Pearce, our chief executive, said: 'While we welcome the news that more people are surviving for longer after a cancer diagnosis, there is still much to be done for those living with and beyond cancer, including lymphoma.'

'As the report rightly highlights, those people who go on to live for a long time after a cancer diagnosis may face additional challenges linked to cancer. We developed our education and support programme, *Live your Life* in response to such needs.'

**To read the report, go to [www.lymphomas.org.uk/](http://www.lymphomas.org.uk/) MacmillanCancerThenAndNow**

Read more...



## New NICE guidelines for non-Hodgkin lymphoma

New guidelines covering the diagnosis and management of non-Hodgkin lymphoma have been published by the National Institute for Health and Care Excellence (NICE). These include a number of new recommendations that could lead to change in practice, most notably for the management of follicular and mantle cell lymphomas.

Treatment is now suggested for follicular lymphoma instead of 'watch and wait' for some people who are not having symptoms. For people at stage 3 or 4, this would be a short course of rituximab, reflecting results of trials that have shown that this delays the time to next treatment. For those at stage 2A who are not able to have rituximab, the first treatment would be radiotherapy. In mantle cell lymphoma, guidelines recommend maintenance rituximab should be continued until the lymphoma gets worse, not stopped after 2 years as is current practice. Maintenance rituximab should be administered for up to 3 years if an autologous stem cell transplant has been given.

In March, the Lymphoma Association called for NICE to withdraw out-of-date guidance and make recommendations that are in line with contemporary clinical practice. Jonathan Pearce, our chief executive comments: 'We are pleased to learn that NICE has responded positively to our comments about baseline PET scans and the use of rituximab for patients with CD20-positive diffuse large-B-cell lymphoma at clinical stage 2, 3 or 4, where CHOP is contra-indicated. Our call for an update to guidance about the use of bendamustine, which is widely used in the treatment of follicular lymphoma, has been acknowledged but not updated as the treatment is currently undergoing a technology appraisal.'

# New Cancer Drugs Fund launched

## A new operating model for the Cancer Drugs Fund (CDF) in England is now up and running

Launched in July, the new system operates as a 'managed access fund' through the National Institute for Health and Care Excellence (NICE) process. NICE can now approve or reject a drug for routine commissioning, or it can give it 'conditional approval'. Under conditional approval, drugs can be made available for up to 2 years while more evidence is being collected to demonstrate the drug's value to the NHS. After 2 years, NICE will assess the new evidence and decide whether the NHS should continue to fund the drug.

Jonathan Pearce, our chief executive, said: 'We welcome the move to improve access to new and innovative treatments and hope the new CDF becomes fit-for-purpose. At this stage, however, we don't know which drugs will remain available through the CDF and, going forward, whether the managed access fund will, in fact, improve access to cancer drugs for people with rare and less common cancers, including lymphomas. We will monitor the implementation of the new system and update our supporters accordingly.'



## NHS Scotland to use ibrutinib

The Scottish Medicines Consortium (SMC) has accepted ibrutinib (Imbruvica®) as a treatment for adults with relapsed or refractory mantle cell lymphoma within NHS Scotland after consultation with the Lymphoma Association.

In England, ibrutinib for relapsed or refractory mantle cell lymphoma remains available via the Cancer Drugs Fund. The Lymphoma Association is involved with the NICE technology appraisal. A final decision on the use of ibrutinib within NHS England will be announced in the coming months.

Jonathan Pearce, our chief executive, said:

**‘The fact that ibrutinib is available within NHS Scotland has now created a postcode lottery and we hope the other UK countries will follow suit and make ibrutinib available.’**

.....



## Stem cell transplants for WM at risk

After a High Court ruling instructing NHS England to fund the HIV prevention treatment PrEP, NHS England have put on hold funding for a number of treatments for rare diseases ‘to ensure that sufficient funding remains available for PrEP’. Stem cell transplants for Waldenström’s Macroglobulinaemia (WM) are one of the treatments affected. NHS England has filed an appeal. In response, the Blood Cancer Alliance, which includes the Lymphoma Association, said in a statement: ‘Transplants for WM patients have been carried out successfully on the NHS for the past 10 years. Withholding these treatments is causing uncertainty and confusion for patients and clinicians. We demand that NHS England reinstates access to these immediately, and a long term, sustainable solution is found so that all patients can continue to access the treatments they need at a cost the NHS can afford.’

For latest news visit  
[www.lymphomas.org.uk/LMBlog](http://www.lymphomas.org.uk/LMBlog)

## Brentuximab draft decision requires urgent review

The Lymphoma Association is calling for urgent review of a draft NICE decision recommending that brentuximab vedotin, used to treat relapsed or refractory Hodgkin lymphoma, is no longer made available via the Cancer Drugs Fund (CDF) at the time of writing. As part of the CDF’s relaunch, NICE is reviewing all 31 treatments currently provided by the Fund. NICE has based its draft decision on there not being enough evidence on the drug’s clinical and cost effectiveness to recommend its use within NHS England.

Jonathan Pearce, our chief executive, said: ‘This draft recommendation is very concerning as it means patients could be denied access to a treatment option that has been successful for a number of patients. We urge Takeda, NICE and clinicians to work together to find a cost-effective solution.’

# Treatment considerations

as we get older

Dr Graham Collins, Consultant Haematologist at Oxford Cancer and Haematology Centre explains how getting older might affect your treatment for lymphoma.



## Lymphoma is more common in older people. There is a sharp rise in incidence after the age of 50, and around half of non-Hodgkin lymphoma cases diagnosed between 2011-2013 were in people over 70.

### Does it take longer to diagnose lymphoma in older people?

In fact, it often takes longer to diagnose lymphoma in younger people, as doctors do not expect them to get cancer.

Many of the symptoms of lymphoma, such as fatigue, night sweats or weight loss could be put down to ageing. A woman with night sweats may think she is experiencing menopause, for example, and older people may feel that getting fatigued is normal.

Doctors sometimes investigate other possibilities first because lymphoma can only be diagnosed with a biopsy, which is invasive.

### Are there specific challenges to treatment as we age?

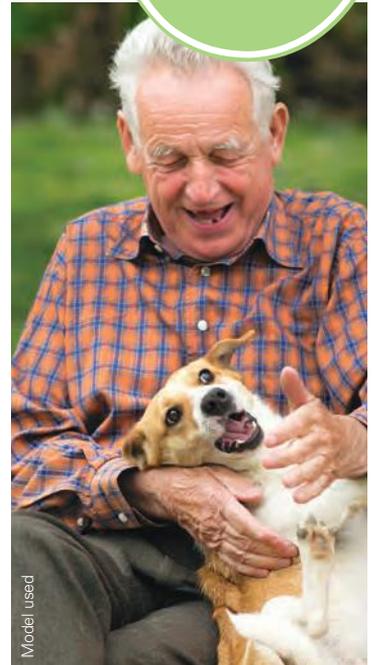
Older age alone need not mean that people are less able to cope with having lymphoma or lymphoma treatments, but it would be wrong to suggest that age does not matter.

The physical changes of ageing might not be noticeable, but they can make people more susceptible to

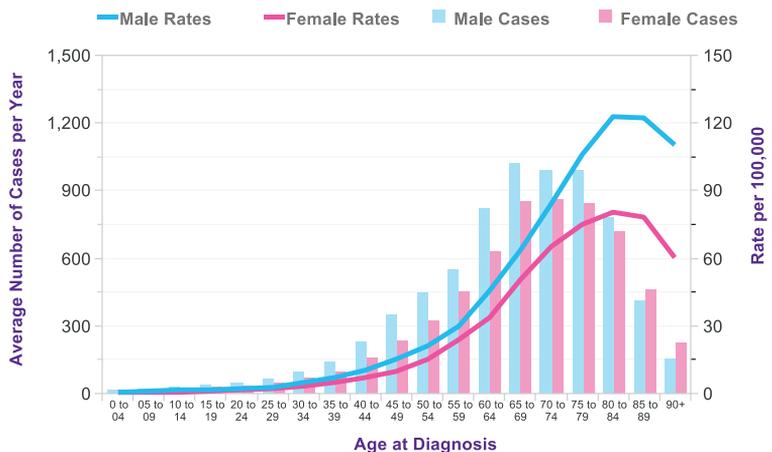
side effects from treatment. How well you are, how healthy your organs are and how ill the lymphoma is making you, all affect how you can be treated.

How well a person's heart, kidneys, liver and bone marrow are working needs to be taken into account when treatment is planned. Older hearts and lungs are less able to withstand strain and are more susceptible to damage by some chemotherapy drugs. As we age our kidneys and liver become less effective. This is important as the 2 main ways of getting rid of chemotherapy are through

Whilst Hodgkin lymphoma is more common in younger people, it affects older people as well



### Incidence of non-Hodgkin lymphoma statistics for 2004-2011 from Cancer Research UK





## There are a number of strategies to improve the way doctors deliver treatment to people as they get older.

our kidneys (by weeing it out) and through our liver. On top of that, your bone marrow reserve goes down as you get older, which means older people are more susceptible to developing low blood counts when they are treated with chemotherapy. In addition, as we get older we are more likely to have other conditions such as heart disease, high blood pressure, kidney problems, diabetes or asthma.

Doctors worry if people live alone, because the risk of infection is serious for people undergoing treatment for lymphoma. It is often a partner who urges the person with lymphoma to get help, and without this prompt there is concern that people will hold off contacting their medical team. This is particularly worrying because if people have no neutrophils then infection can take hold

very quickly. It is important that anyone seeks help immediately if they become unwell.

### **Considering the best treatments**

There are a number of strategies to improve the way doctors deliver treatment to people as they get older. An assessment is important – looking at age, how the heart, gut, kidney and liver are functioning, memory, how well they manage day-to-day tasks and how much support they need at home. Another important factor is whether the person has any other illnesses or conditions, how severe these are and how they are being treated.

Doctors can use several tools to assess a person's treatment options, ranging from the very comprehensive to something fairly basic. At the simplest level, the doctor considers

how people come into the room - are they walking unaided or with a stick? How well do they look? This can be a helpful indicator of general health. Other tools will probably be developed in the future, perhaps with mobile applications measuring how active people are, but that is to come.

The team also assess how ill the person is when they are diagnosed, what symptoms they are having and what parts of the body have been affected by the lymphoma. All these factors determine the most suitable and safest treatments, not just someone's age.

### **Chemotherapy**

One of the most commonly used chemotherapy regimens for non-Hodgkin lymphoma is R-CHOP, which involves several drugs; rituximab, cyclophosphamide,

doxorubicin (hydroxy-daunomycin), vincristine (Oncovin®) and prednisolone (a steroid). R-CHOP, like any other treatment, carries risks: doxorubicin can cause heart failure and is limited to 9 doses in total for anyone, although most people have no more than 8. Anyone over the age of 70, or with a history of high blood pressure or heart problems, will be given a heart scan to check the health of their heart before being given CHOP.

The steroid prednisolone will cause blood sugar to go out of control which is a problem for anyone with diabetes. Although this is not necessarily dangerous, the person will feel less well and it can be stressful. The steroid can affect memory, which naturally becomes less sharp as we age anyway.

Vincristine (Oncovin®) can cause nerve problems (peripheral neuropathy), which can be troublesome in older people, especially if they already have nerve damage.

One approach may be to reduce the doses, replacing R-CHOP with mini-CHOP plus rituximab. This can be quite effective and is fairly well tolerated.

For people between the ages of 70 and 80, clinicians make a judgement based on the fitness of the person. For those fit enough, the full dose works better, but for

those less fit and those over 80, a reduced dose is better.

There are also other chemotherapy drugs that can be given. For people who have heart problems, clinicians may replace R-CHOP with a regimen called R-CVP which protects the heart but can cause neuropathy.

Someone with chronic lymphocytic leukaemia (CLL) would usually have FCR (fludarabine, cyclophosphamide and rituximab) as standard first-line treatment. But if they are frail, bendamustine and rituximab would be given as an alternative. For anyone who is really frail, chlorambucil with or without an antibody treatment (such as rituximab) would be considered.

### **Is there flexibility in treatment?**

Doctors usually monitor older people closely to see how well they are tolerating their treatment. Clinicians

may start with a certain approach and make changes if necessary, either reducing or increasing drug dosage.

### **Stem cell transplants – are they an option?**

Doctors routinely carry out transplants on people up to 70 and, occasionally, beyond. In the past, allogeneic transplants involved very high doses of chemotherapy and total body irradiation. As a result this procedure was considered unsuitable for people over the age of 40. Today doctors often use lower doses of chemotherapy, which is called reduced-intensity condition or RIC. In a RIC transplant they rely less on the strength of the chemotherapy and more on a phenomenon called the 'graft-versus-lymphoma effect'. This is an immune reaction in which the grafted stem cells attack the lymphoma cells in the person who receives the transplant. However doctors keep in mind a possible side effect of allogeneic stem cell transplants, graft-versus-host disease (GvHD).

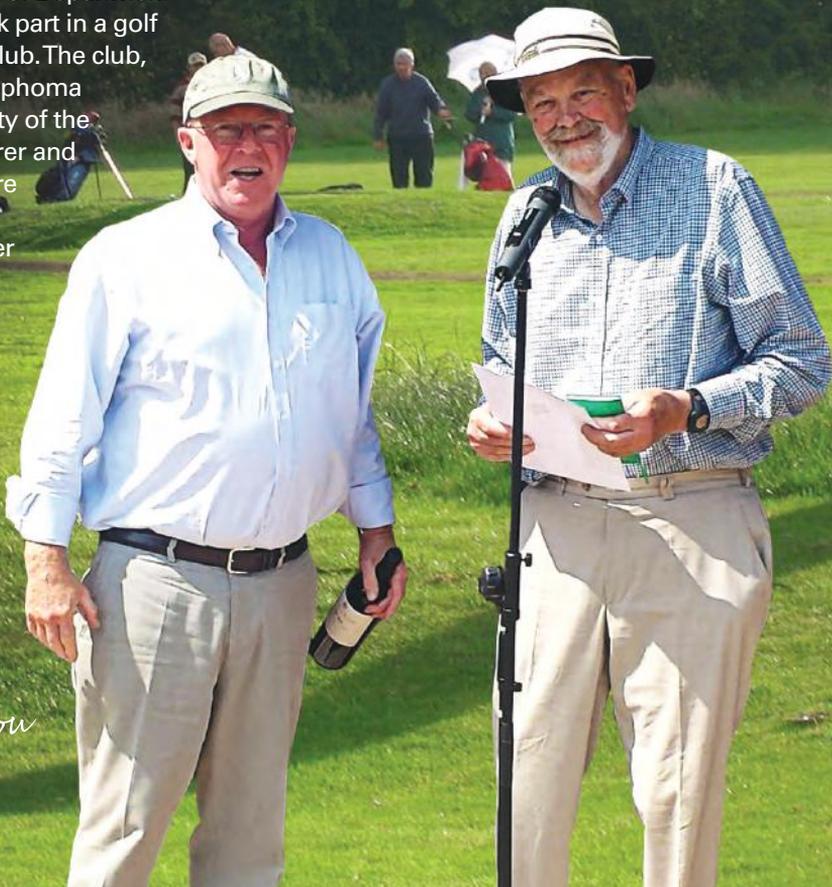
## **> Would you encourage older people to enter a clinical trial?**

We would encourage people to enquire about clinical trials, as generally older people are underrepresented, which means we don't know how new treatments or approaches will affect them. All trials have eligibility criteria which may exclude people based on medications they may have taken, co-morbidities or age. However, some trials are specifically for older people or people with co-morbidities. For example the average age of people entering a clinical trial called INCA is 81.

# Beat the Treasurer and Professor

Professor David Linch, Head of Department of Haematology at UCL, took part in a golf challenge at Denham Golf Club. The club, which is supporting the Lymphoma Association as its 2016 charity of the year, held a 'Beat the Treasurer and Professor' competition where members and their guests challenged the Club Treasurer Rob Walther (pictured right with Club Captain Peter Sedgwick) and Professor Linch to a 2-ball better contest. Rob, who is now in remission was treated by Professor Linch and his team. The event raised more than £7,500 for the Lymphoma Association and we thank everyone who took part and helped host the day.

*thank you*



## Getting involved, raising funds

We are always humbled and amazed by the range of activities and events that our wonderful supporters get involved in to raise funds.

The number of people diagnosed with lymphoma each year is growing and we need help to make sure that everyone affected can receive the specialist information and support they need.



## From London to Paris

In June, Graham Franklin (pictured centre), took on the 325-mile cycle ride from London to Paris to raise money for the Lymphoma Association in support of his brother-in-law, Alan. Graham said: 'It was the most fantastic experience' and would like to thank all his amazing supporters for helping him to raise over £8,000. We, too, would like to add our very grateful thanks.



## In memory of Amy

Our warmest thanks go to the family and friends of Amy Yates, who have raised over £17,000 in her memory through donations to Amy's online Tribute Fund, a Mercedes AMG F1 eBay auction, a fundraising day and sponsorship from the Great Bristol 10k run. Amy passed away in February 2016, aged 30 after a 7-and-a-half year fight against lymphoma. [www.lymphomas.org.uk/tribute-funds](http://www.lymphomas.org.uk/tribute-funds)



If these stories have inspired you to get involved and join us in supporting people affected by lymphoma, visit [www.lymphomas.org.uk/GetInvolved](http://www.lymphomas.org.uk/GetInvolved) or call the fundraising team on 01296 619419 for a free fundraising pack.

*thank you*

## 9 countries in 4 days

Congratulations to Eddie Wilkinson and Andy Mortimer who have raised £1,000 for the Lymphoma Association by taking part in the Two Ball Banger Rally in August – just weeks after Eddie finished chemo. The route took them across 9 countries in 4 days and saw them completing outrageous daily challenges to test their resilience, teamwork, driving and navigational skills.

A photograph of Lord Campbell, an older man with glasses, wearing a dark suit and a blue patterned tie. He is smiling and looking towards a woman in a red dress who is also smiling. Another woman in a black and white polka-dot top is seen from the back, looking towards the other two. The background is a dimly lit room with red patterned wallpaper and framed pictures.

LORD CAMPBELL

# ‘I am delighted to be Patron of the Lymphoma Association’

We are proud to announce that  
Lord Campbell CH CBE PC QC has become  
Patron of the Lymphoma Association.

# Some of his greatest achievements have been since his lymphoma diagnosis in 2002.

Lord Campbell's career is an esteemed and varied one. In 1964 he competed in the 200 metres and 4 x 100 metres relay at the Tokyo Olympic Games, and he held the British record for the 100 metres sprint from 1967 until 1974.

In those days, Olympic sportsmen and women were amateurs, so he then had to focus on his legal career, being called to the bar in Scotland in 1968 and in 1982 he became a Queen's Counsel. But his enthusiasm for sport never waned and he was delighted to be invited to be a member of the London 2012 Olympic Board.

Lord Campbell is probably best known as a Member of Parliament (MP). He was first elected to Westminster in 1987 for the Scottish constituency of North East Fife. He went on to become the Liberal Democrat chief spokesperson for foreign affairs and defence, deputy leader in February 2003, and party leader from March 2006 until October 2007. He is presently Chancellor of the University of St Andrews.

Last year Menzies Campbell stepped down as an MP and received a life peerage, becoming Baron Campbell of Pittenweem and a member of the House of Lords where he continues to follow his interest in foreign affairs.

## 'The signs were there, but a diagnosis of lymphoma still came as an enormous shock'

In 2002, I was having some pain in my right hip, which got worse over time. After about 6 months, the pain was making it difficult for me to walk, so I was referred to an orthopaedic surgeon. He thought the pain was caused by back problems, which could be helped with physiotherapy. I went to a sports physiotherapist, but after 2 visits he said he felt sure that the problem was not in my back, but in my hip. By now it was acutely painful. I was also losing weight.

I was referred back to hospital to have further X-rays of my hip. I distinctly recall being in the room with 3 consultants explaining that I would have to be transferred to another department immediately to be properly assessed and diagnosed. Alarm bells were ringing.

I was told I had a malignant tumour on my hip. Although I should have suspected something like this, I broke out in a sweat and almost fainted. I just wanted to leave in the hope it would all go away. I didn't



### Did you know?

In 2013, there were 13,413 new cases of non-Hodgkin lymphoma in the UK of which 54% were in men.

Source: Cancer Research UK

want to tell people at the time, but because of my parliamentary responsibilities I knew I needed to tidy things up in London to make way for my treatment. While in London I was contacted by the haematologist who would be treating me. I was back in Scotland within a couple of days to meet him.

He explained that I had non-Hodgkin lymphoma with a primary bone tumour on my acetabulum (the socket of the hip bone).

I deliberately did not research my condition on the internet and even to this day don't know what subtype of non-Hodgkin lymphoma I had. I simply knew I was to have chemotherapy followed by radiotherapy.

From the start, I had every confidence in my consultant and was happy to leave my care in his hands. In fact, the more I thought about it, the less inclined I was to know any of the detail. I was sure he would provide me with the best care.

Although I had not wanted to make it public, I felt sure the story would leak and I wanted it to be accurate. I drafted a press release and showed it to my haematologist to confirm that what I was saying was correct.

This was a really difficult time politically and I found it

very hard to be away from Parliament. It was just prior to Tony Blair and George W Bush agreeing military action against Saddam Hussein. As the Liberal Democrat chief spokesperson for foreign affairs and defence, I was opposed to military action (as were the party) and I felt a huge responsibility and obligation.

While undergoing treatment, I appeared on TV and wrote several newspaper articles. These were a distraction and made me feel involved, which helped me to cope with the lymphoma emotionally. In addition, my constituents were very sympathetic and understanding, although my constituency office was having to work its socks off.

For me, there were real benefits to being at home, which I cannot overstate. I had excellent treatment, tremendous support from my wife, family and friends, which made such a difference, and I also had good luck.

### **‘I thought I coped well with treatment, but by the end I felt really wretched’**

Treatment started straight away. Although chemotherapy was usually given on a 3-week cycle, my consultant explained that they had a trial with a 2-week chemotherapy cycle.

He explained it would be tougher, but he felt I was fit enough to withstand it.

I coped well with the chemotherapy in the beginning, but towards the end I was in pretty poor shape. I couldn't eat because of the chemotherapy so I had to have build-up drinks to help. I felt really wretched and quite nervous.

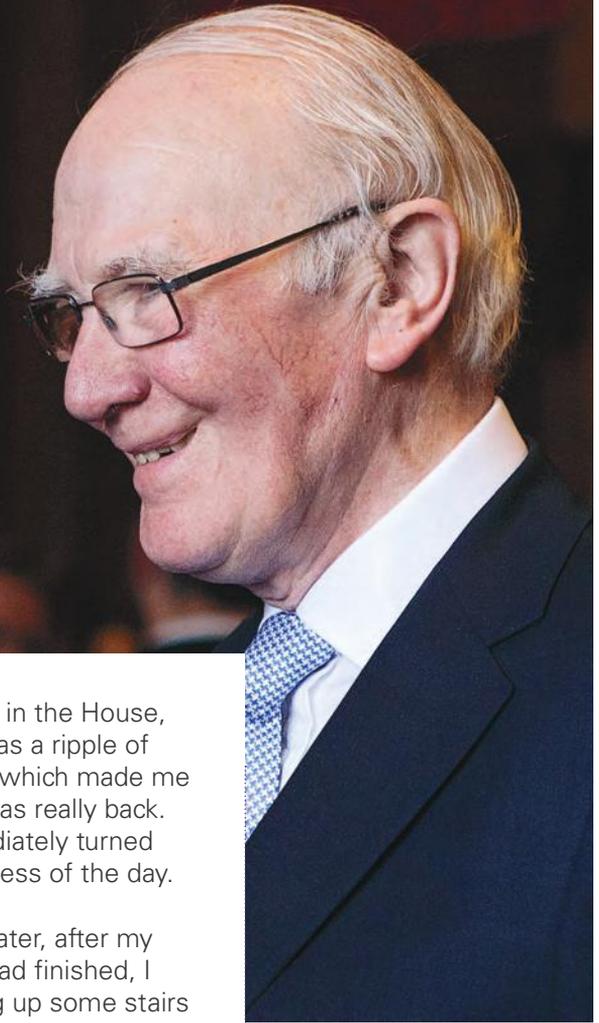
Half-way through treatment I had a scan and was told that the tumour had shrunk far more than could have been hoped. My wife and I both felt really reassured. It felt like things were going in the right direction and we went out to lunch and drank champagne, although it tasted like vinegar to me.

While I was undergoing treatment in 2003, the deputy leader stepped down. I got on a train to London, spoke at hustings for the deputy leadership and was elected. Looking back now it seems quite bizarre to have done that.

The scan at the end of chemotherapy showed no sign of the tumour, to the relief of myself and my wife.

Chemotherapy was followed by radiotherapy. Compared with the chemotherapy, the radiotherapy was straightforward. I had to have it 5 times a week for 4 weeks, and always at 11am.

## ‘I’ve been struck by the strong bond you develop with your medical team’



During this period, there was a debate and vote in the House of Commons on Iraq and I desperately wanted to be there to vote against military action. I explained this at the radiography clinic and they scheduled my appointments to allow me to travel to London and return without missing a radiotherapy session.

### ‘Going back to the House of Commons was really emotional’

Radiotherapy came to an end during the Easter recess of 2003. Going back to the House of Commons for the first time was really emotional. On my first day, I stood up to ask a question in the usual way. Clapping is not

encouraged in the House, but there was a ripple of ‘hear, hear’ which made me feel that I was really back. But I immediately turned to the business of the day.

Sometime later, after my treatment had finished, I was walking up some stairs and felt breathless. I thought nothing of it, but after investigation I was told that I had suffered some heart damage as a side effect of the treatment. I now have to take medication for my heart condition and have a defibrillator implanted. But in spite of all this, I live a perfectly normal life.’

**Lord Menzies  
Campbell**



### Did you know?

**In Great Britain non-Hodgkin lymphoma incidence rates have increased 160% since the late 1970s.**

Source: Cancer Research UK



# Should I seek a second opinion?

Most people diagnosed with lymphoma are confident in their consultant and their medical team and their care is likely to be very good. Occasionally, however, people might want to ask another doctor for an opinion on their diagnosis or treatment.

## Decisions on your care are made in consultation with others

Your diagnosis and care are not carried out by just one person and your treatment is not managed in isolation.

Several specialists are involved in making the diagnosis before treatment starts. Your consultant haematologist or oncologist, one or more pathologists who study the biopsies taken and the radiologists who report the scans all contribute their expertise.

Prior to treatment, your case is discussed at a multi-disciplinary team meeting (MDT) which recommends the best treatment for you based on local and national guidelines and considering your individual circumstances. MDTs include consultant haematologists and other members of the health team who are available to give advice to the MDT where needed. So, in fact, several opinions have already been sought before your lymphoma is diagnosed and your treatment plan drawn up.



## Did you know?

Several opinions have already been sought before your lymphoma is diagnosed and your treatment planned.

## Ask all the questions you need

The more knowledge you have, the more you can share in the decision making, so it is important that you feel able to ask as many questions as you wish and that you feel confident in the decisions your doctors are making. Your team will be happy for you to ask lots of questions, even if you ask more than once. If you still feel you have not had enough time with your specialist – or still don't understand something – try talking to another member of the team; perhaps your nurse specialist. If they can't answer your concerns, they can talk to the specialist on your behalf about your worries.

## How can you get a second opinion?

If you would still like another opinion, discuss this with your consultant or a member of the team. Your doctor won't take offence at your seeking another opinion and it should not alter your relationship with them. Explain why you want a second opinion and what questions you need answered. It is worth asking for advice on who they recommend you go to, even if you have a consultant in mind. You can also ask your GP to refer you to another consultant or hospital. The new consultant will be told that this is your second opinion.

Seeing another doctor does not necessarily mean that they will take over your case – they might just communicate their opinion or recommendations to your current specialist. If you want to be treated by a new team, this has to be arranged formally between the 2 hospitals. Your specialist will then send any test results and information on any treatment you have already had to the new team so they have a clear picture of your situation. You should discuss the pros and cons of a move like this with your medical team before going ahead.

## Find out about clinical trials

If there is a possibility that you could take part in a clinical trial, this should be discussed with you. You can look up websites and discuss any trials you believe you may be eligible for with your doctor. There are a number of things to consider before entering a clinical trial, such as additional travel. More information on clinical trials can be found at [www.lymphomas.org.uk/TrialsLink](http://www.lymphomas.org.uk/TrialsLink).

If you want to know more about clinical trials, go to our new information service at [www.lymphomas.org.uk/TrialsLink](http://www.lymphomas.org.uk/TrialsLink) (see details on back cover)

## The main reasons why people consider asking for a second opinion are:

- To find out if the diagnosis is correct.
- To make sure you are having the best treatment.
- If treatment is changed during the course of the illness, for example if the lymphoma is not responding as hoped, if the lymphoma has relapsed (come back after treatment) or is refractory (does not respond to treatment).
- If you have a rare type of lymphoma and would like to speak with someone with more experience of treating that specific subtype. Note that your specialist may have already asked for an opinion from a doctor with particular expertise in that lymphoma.
- If you would like to investigate your eligibility to take part in a clinical trial.
- If you find it difficult to talk to the specialist you have been referred to, or do not feel they are giving you enough information about your illness or treatment.

**With thanks to Dr Pam McKay, Consultant Haematologist at the Beatson West of Scotland Cancer Centre, Glasgow for her help in writing this.**



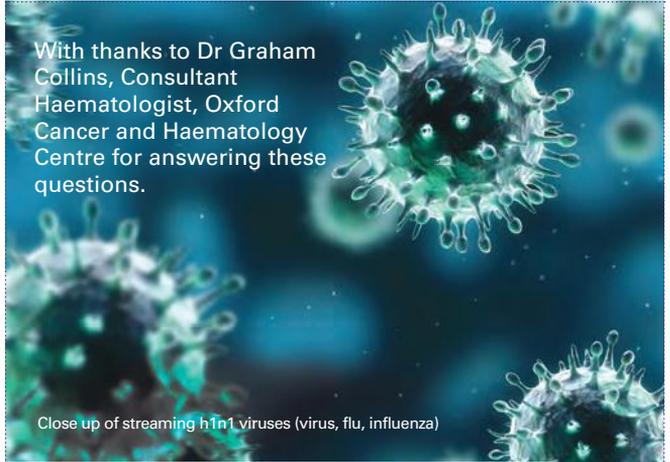
## ask the experts

### Can I have the 'shingles' jab?

The shingles vaccine or jab is routinely available to people aged 70 and 78. This will reduce the risk of shingles – a common and painful condition in older people. Unfortunately because it is a live vaccine, the shingles vaccine will not be safe for many people with lymphoma, who have a weakened immune system.

If you are offered the shingles jab, for example when you attend for your flu jab, do remind the staff that you have lymphoma. If they continue to recommend the shingles jab, make sure that they have checked with your specialist first.

In addition, you should avoid having any direct contact with other people who have received the shingles vaccine if they have developed a rash after their vaccination. This is because live virus can be shed from affected areas of skin. Close contact should be avoided in this situation until all the spots are crusted or the rash has gone away.



With thanks to Dr Graham Collins, Consultant Haematologist, Oxford Cancer and Haematology Centre for answering these questions.

### Should I have a flu or pneumonia jab?

You are recommended to have an annual influenza vaccine (flu jab) if you have lymphoma, if you have had your spleen removed (splenectomy), or 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.

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.

The pneumococcal vaccine (pneumonia jab) is active against a bacterial infection that can cause pneumonia, meningitis and septicaemia. These infections are particularly serious in people with a suppressed immune system. It is not a general protection against all forms of pneumonia, just pneumonia caused by the 'pneumococcus' organism.



An exciting new event has been taking place across the country. Gung-Ho! is the most hilarious inflatable 5k obstacle course the country has ever seen! To help mark our 30th anniversary year as a registered charity, a staff team from the Lymphoma Association, led by our chief executive Jonathan Pearce, and our charity of the year partner The Share Centre took on the challenge this summer. A team from the Western General Hospital also took part in Edinburgh. As Jenny Jacob, Staff Nurse at Western General exclaimed: 'Wow - honestly I don't think there are actually words to describe how fabulous Gung-Ho! was.'



Other individual supporters have also taken part in Gung-Ho! events across the country including Jayne Lyell and Paul Brennan in Newcastle and Zoe Bennett and Richard Wells in Sandwell Valley. Over £2,200 has been raised to date.

For the chance to laugh yourself silly, find out more at [www.lymphomas.org.uk/GungHo](http://www.lymphomas.org.uk/GungHo)

### Walking challenges 2017

Walking is undoubtedly the best way to take in the sights and sounds of Britain's most stunning locations and with routes of up to 100km, every individual's endurance can be put to the test. Join Team Lymphoma and explore the best of Britain whilst supporting people affected by lymphatic cancer.



To sign up for events including the South Coast Challenge, Thames Path Challenge, Isle of Wight Challenge and the Three Peaks Challenge, visit [www.lymphomas.org.uk/Walking](http://www.lymphomas.org.uk/Walking)

**Teresa explains what an emotional rollercoaster it was when her daughter Victoria was diagnosed with Hodgkin lymphoma.**

'In June 2015 my daughter Victoria mentioned that she had a lump in her neck. It wasn't visible, it didn't hurt, but it was rock hard. I told her that it was probably nothing

The CT scan revealed a lump in Victoria's chest as well as her neck. It was agreed the lump in her neck would be surgically removed. The operation went well and Victoria received a call a week later from haematology asking her to go in the next day. Both my husband and I went with Victoria to see

Victoria had planned to open a hair salon for many years and at 36 everything had been coming together. She had found a shop and was planning its refurbishment, but now she was receiving treatment and the contract was due to be signed. She asked her doctor what she should do. He suggested she should take on the shop and plan for the future.

# Victoria's story

to worry about. On reflection, I can't believe I said that!

Sadly that August Victoria had a miscarriage. She mentioned the lump in her neck and her doctor immediately referred her to an ear, nose and throat specialist. Initial investigations didn't reveal anything, so an ultrasound scan and a needle biopsy were arranged. The 2 week wait for the results were worrying, but after a fortnight Victoria was told they would need to repeat the biopsy. The second biopsy didn't show anything, so a CT scan was organised. Victoria was feeling increasingly tired, although she put it down to looking after her 3-year-old son Thomas as well as working.

the haematologist. He calmly explained that the biopsy had shown she had Hodgkin lymphoma, a type of blood cancer. Her face filled with tears. We sat with the Clinical Nurse Specialist and shed lots of tears and drank lots of tea. She explained that chemotherapy would start the next week. In the meantime, a PET scan was arranged to stage the Hodgkin lymphoma.

Victoria started ABVD chemotherapy which would be given fortnightly. She felt sick when she had the first chemotherapy, but this was quickly dealt with. In fact she managed really well and, although her hair went a bit finer, she didn't lose it.

Her husband Gavin and his friend were fantastic. Despite having jobs themselves, they worked on Victoria's plans to make the salon into her vision, organising the décor and buying equipment.

After 2 cycles of ABVD Victoria had a PET scan to see how things were going. Unfortunately things were not going as well as expected. This was a massive blow as we all thought she was doing so well. Our confidence was completely knocked. Victoria's consultant explained that they were going to change her chemotherapy to a more aggressive one, escalated BEACOPP. She would need to stay in hospital for the treatment. This was difficult for her with a little boy. She explained to Thomas that mummy was ill and needed to stay in hospital. Because she had a PICC line in, Thomas thought it was her arm that was poorly and

focussed on that; her nurse put a plaster on his teddy's arm.

Victoria's first treatment with escalated BEACOPP made her feel very sick and her hair fell out within 4 or 5 days, which she found really distressing. She felt her first wig just looked wrong; it had too much hair and no style. She bought another one and found a Trevor Sorbie salon to have it styled. Her blonde bob was beautiful and it was amazing how much of a difference this made. I still recall just how glamorous she looked throughout.

Working with Gavin, she continued to plan the salon, and after 2 cycles of the escalated BEACOPP, had a PET scan. This showed she was in remission. It was fantastic news, but she still had to have the other 2 cycles.

She really struggled with the last 2 cycles. I recall visiting her in hospital; she looked so pale and her eyes were dark and sunken. I can't begin to explain how hard it is for a parent to see their child so ill. After her last chemotherapy, she decided the salon would open 2 weeks later. She called it Frederico's in memory of her grandad who she adored. She is going to take the Trevor Sorbie course for wig cutting and styling and looking after hair as it is growing back. She feels in this way she can help others going through a similar situation.'

Our revised Hodgkin lymphoma book is now available [www.lymphomas.org.uk/HLBook](http://www.lymphomas.org.uk/HLBook)



**'The salon is beautifully designed and is doing well. I can't even tell you how proud I am of my daughter Victoria.'**



## Pre-discovery and drug discovery

5,000-10,000 drugs  
Around 4-5 years

## Pre-clinical tests

10-20 drugs      Around 1 year

## Clinical trials

Phase 1: 5-10 drugs  
Phase 2: 2-5 drugs  
Phase 3: 1-2 drugs  
Around 6 years

## Approval and funding

1 drug  
Around  
1-2 years

Professor Graham Packham's research group at the University of Southampton studies how lymphocytes become out of control and looks at the response of lymphoma cells to new drugs.

He says: 'Our current drug development work focuses on identifying the essential signalling pathways that keep cancerous blood cells alive in diseases like chronic lymphocytic leukaemia and follicular lymphoma. We also study new drugs that can block these pathways to see what effects they have on lymphoma cells. Our aim is to contribute to a better understanding of the biology of cancerous blood cells and how new drugs work so that we can identify which drugs work best for each individual patient.'

Data sourced from ABPI (read at [www.lymphomas.org.uk/ABPI](http://www.lymphomas.org.uk/ABPI)).

# Drug development: from bench to bedside in around 12½ years

Professor Peter Johnson specialises in the treatment of lymphoma and is the chief investigator for several lymphoma trials. He leads the Southampton Cancer Research UK Centre.

He says: 'My clinical team works closely with the laboratory research groups. Understanding the biology of a cancer gets

us to the starting line, but quite often what happens to people is different to what we see in the lab, so we are always learning. Things sometimes go faster than we expect too, and then there is intense research in a certain area. Examples of this are the checkpoint antibodies at the moment (eg pembrolizumab and nivolumab). These are drugs that alter the switches of the immune system and are showing promise in Hodgkin lymphoma and other cancers too.'



**New, targeted therapies aim to target lymphoma cells more precisely than chemotherapy, reducing the effects on normal cells. There is much excitement about these drugs, but drug development and approval is a long and expensive road.**

It can be frustrating hearing about new drugs that could improve outcomes for people with lymphoma when these are not yet available to you. The time and cost to develop a drug vary hugely, but on average, it takes around 12½ years and £1.15 billion for a large pharmaceutical company to take a drug from discovery to approval. For each drug that gets approved for use in lymphoma, thousands have already been tested.

The development of a new drug involves:

**Pre-discovery:** research to understand a disease underpins the search for possible drugs - it helps to identify targets for a drug to act on.

**Drug discovery:** researchers search for drugs that act on the targets they've identified.

**Pre-clinical testing:** before a drug can be tested in humans, it undergoes extensive testing in laboratories and on animals.

**Clinical trials:** although pre-clinical testing helps to identify possible side effects of drugs and gives researchers an idea of the best dose to start with, these findings have to be tested thoroughly in people with the disease.

Many trials are international, where the drug is tested in several different countries as part of the same trial. This is

because it is difficult to recruit enough people with rarer types of lymphoma to conduct a trial in just one country.

**Approval:** If clinical trials show that a new drug significantly improves outcomes for people with lymphoma, the drug company applies for the drug to be approved (licensed) for use. The drug company has to apply to different authorities in different parts of the world, eg the Food and Drug Administration (FDA) approves drugs in the US. While in Europe, the European Medicines Agency (EMA) assesses applications and recommends whether drugs should be licensed. The European Commission (EC) then makes a decision. Once a drug is licensed, national authorities decide whether it will be funded in their country, eg on the NHS in the UK.

In the last few years, several targeted therapies have been approved for people with lymphoma, eg ibrutinib, brentuximab vedotin, and lenalidomide, among many others. There are many more in development.

**Treatment trials are done in phases:**

- ✓ Phase 1 are small trials to help find the best dose or test safety.
- ✓ Phase 2 find out more about the safety and effectiveness of a drug. In rare types of lymphoma, phase 2 trials can be pivotal in getting approval of a drug.
- ✓ Phase 3 are large trials that often test a new treatment against the standard treatment. These trials need a lot of people to take part so it is difficult to do phase 3 trials for rare types of lymphoma.



**Read more about clinical trials or search our new clinical trials database Lymphoma TrialsLink at [www.lymphomas.org.uk/TrialsLink](http://www.lymphomas.org.uk/TrialsLink)**

*Read more...*

# Update on T-cell lymphomas

**Lymphoma can develop from a B cell or a T cell, but B-cell lymphomas are much more common. Only around 1 in 10 cases of non-Hodgkin lymphoma (NHL) develop from a T cell.**

.....

**The State of the Art: Update on T-cell Lymphomas meeting in Leicester in March 2016 brought together specialists from across the UK to discuss developments in the diagnosis and management of this rare yet diverse group of lymphomas.**

## **What's new in treatment?**

CHOP chemotherapy (cyclophosphamide, vincristine, doxorubicin and prednisolone) remains the backbone of treatment for most T-cell lymphomas. As it is common for many types of T-cell lymphoma to relapse (come back) experts are looking to improve outcomes. Options under consideration include:

- ✓ different chemotherapy, eg, adding etoposide to CHOP (CHOEP) or using a regimen that includes gemcitabine
- ✓ autologous or allogeneic stem cell transplant at remission or after relapse
- ✓ newer targeted drugs alone or in rational combinations

based on the biology of the disease.

The only way to find out which treatments work best is through clinical trials. However, hospitals need to work together as carrying out trials in T-cell lymphoma is challenging because of the rarity of these diseases. There are some newer treatment regimens now being used for certain types of T-cell lymphoma:

- ✓ Asparaginase-containing chemotherapy regimens have transformed the outlook for **extranodal NK/T-cell lymphoma**. Radiotherapy early in the course of treatment is also important and a stem cell transplant is usually recommended.
- ✓ Some people with **ALK negative anaplastic large cell lymphoma (ALCL)** might benefit from adding etoposide to CHOP (CHOEP) to improve outcomes. For those whose disease comes

back or doesn't respond to treatment, brentuximab vedotin is considered a game-changing treatment and is available through the Cancer Drugs Fund in England, but only through an individual funding request in the rest of the UK.

- ✓ **Adult T-cell leukaemia/lymphoma (ATLL)** is difficult to treat, with people often relapsing quickly after treatment. Combinations of the antiretroviral drug zidovudine and IFN alpha may improve outcome.

In the US, several targeted therapies are already approved for T-cell lymphoma. Options are limited in the UK and access to newer treatments is only usually possible through a clinical trial. However, the newer drugs in development for T-cell lymphoma give promise of a brighter outlook for people with these rare types of lymphoma.

With thanks to Dr Graham Collins, Consultant Haematologist at Oxford Cancer and Haematology Centre.



**The Lymphoma Association has recently updated information about specific types of T-cell lymphomas. Go to [www.lymphomas.org.uk/TCell](http://www.lymphomas.org.uk/TCell) to find out more.**

# And *then* again...

Ron talks about the challenges of relapsing lymphoma and how he was instrumental in the introduction of a new drug



**'I was 57 and had taken early retirement from the Civil Service 2 years earlier with intentions of looking after my wife Katherine who had health problems over a number of years. We were living in Somerset, but had been planning to move to North Lincolnshire.**

In 2005 I noticed a lump in my testicle so went to see my doctor and from there everything happened very quickly. I was referred for a scan, as my doctor suspected testicular cancer. However the results from the scan and a biopsy revealed that I had diffuse large B-cell lymphoma.

**Strangely I wasn't shocked by the news. I think by then I had come to the conclusion that it was cancer.**



I was treated with R-CHOP chemotherapy which I tolerated pretty well. At least I thought I had, although others told me I was a bit more snappy and bad tempered, and looked very ill. I experienced side effects, with my hair dropping out. I was also really aware of how fatigued I became. This was easy to measure as where we lived was very hilly; my walk into town was down a steep hill, but I found the hill on the way back increasingly difficult and had to sit down to get my breath back.

Despite the diagnosis and treatment, we decided to carry on with the house move which eventually came together just before my final course of chemotherapy. I thought it would keep things more straightforward to have the last treatment in the same hospital as the previous treatments. Looking back, I'm not too sure how I managed that! The chemotherapy was to be followed by radiotherapy, so treatment was moved to our new location.

The house we bought had been described to us as in a quiet and peaceful spot.

## How you can help support medical advances

If you would like to share your experience to support our advocacy work or when making submissions to support drug approval, please contact us on 01296 619400 or email [enquiries@lymphomas.org.uk](mailto:enquiries@lymphomas.org.uk)



'I thrive on being busy. We breed King Charles Spaniels and at one point we had 12 dogs. I was also Chairman of the Kennel Club Gazette editorial board until earlier this year.'

Diffuse large B-Cell lymphoma is the most common kind of high-grade non-Hodgkin lymphoma

But when we moved in, the youth club next door was a nightmare. Within a month, I was having meetings with police and local councillor's and set up a neighbourhood watch. This immediately got me involved in the community. So much so, that I became a councillor, and in 2014 was elected Mayor of Crowle.

Throughout all this, my lymphoma was persistent. In 2007 it came back and on this occasion my medical team decided to harvest stem cells in case I relapsed and needed an autologous stem cell transplant, using my own stem cells. This proved to be the case in January 2009 and I found the transplant to be the hardest experience I had. It took me months to recover. In April 2010 I was diagnosed with lymphoma for the fourth time, leading to a 2-year

programme of maintenance rituximab. This was followed by another 2 year cycle in 2014. Half way through another lump appeared which was treated with radiotherapy because it was localised. But within a month the lymphoma was back again very close to where it had been treated, so I then needed another course of chemotherapy.

### Involved in a NICE submission

The Lymphoma Association got in touch with me in 2012 because they had been invited by NICE to make a submission. This was in support of a chemotherapy drug called Pixantrone which is used to treat non-Hodgkin lymphoma when a person has relapsed or has refractory disease (where treatments are no longer working). I was pleased to have the opportunity to share my experience and I

understand from the Lymphoma Association that this was a powerful addition to the submission.

I had occasion to use Pixantrone myself when my lymphoma relapsed again in 2015. I spoke to my doctor, who was aware of the drug, and agreed it would be suitable for me. Unfortunately the Pixantrone did not work for me, although I know that not everything will work for everyone. I then went on to have Etoposide, which has since been discontinued, followed by another course of radiotherapy.

It has felt fairly non-stop, but on each occasion a suitable treatment has been found, so I am delighted to have been able to support the addition of another drug for people with relapsed or refractory lymphoma.

1,590 people  
liked, retweeted  
or clicked on  
our tweets

27,794  
people visited  
our website

5,820  
people commented,  
liked or shared  
our Facebook  
posts

# Lymphatic Cancer Awareness Week 12-18 September 2016

This year's Lymphatic Cancer Awareness Week has been our busiest yet. Thank you to everyone who helped raise awareness of lymphoma in 2016.

Thank you so much to all of you who have already supported our Great Purple Collection this LCAW 2016. We're already a third of the way to reaching our target of £15,000! If you've not made a donation yet, please do so if you can. Every gift great or small is appreciated, and it all adds up! Please go to [www.lymphomas.org.uk/coinbox](http://www.lymphomas.org.uk/coinbox) to help improve services for everyone coping with lymphoma.

285 LCAW  
packs were  
sent out

2,065 people  
completed our 'What's  
your type?' survey to  
help us improve our  
support and services

By the end of September,  
over 1,600 of you completed  
our online survey calling on  
NHS England to conduct  
a data audit



Chief executive Jonathan Pearce (pictured with Clare Ratchford, member of Manchester support group) visited the Wigan support group during LCAW.



The Manchester support group had a stand at their local supermarket, attracting great interest from members of the public.

# Information & Support Services

We know that people seek support in different ways. You may already know about our dedicated Freephone helpline or that you can email the information and support team. But do you know about the other ways to contact us, our buddy scheme or the online support available?

## Live chat

You can have a confidential, one-to-one chat online with a member of our team to ask questions or talk through any concerns. If you live in the UK or Channel Islands, go to [www.lymphomas.org.uk](http://www.lymphomas.org.uk) between 9am and 5pm Monday to Friday. You should see a message at the bottom right corner. Just start typing in the text box to use the Live Chat facility. If Live Chat is offline, simply leave a message for us and we'll get back to you.



## Buddies

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.

Our online forums will welcome you any time of day or night and are a great place for support and to talk to others with shared experiences. With over 1,500 topics you should be able to find a conversation to join, or raise a topic you'd like discussed.

## Forums

## Lymphoma Association Support Groups near you

Aylesbury  
Bangor  
Bath  
Cambridge  
Canterbury  
Cardiff  
Cheltenham  
Colchester  
Colne  
Coventry  
Derby  
Driffield  
Frodsham  
Glasgow  
Guildford  
Kendal  
Lancaster  
Leeds  
Leicester  
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  
Wigan  
Lymphoma Association Support North 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](mailto:information@lymphomas.org.uk) or visit our website at [www.lymphomas.org.uk/LASupportGroups](http://www.lymphomas.org.uk/LASupportGroups).

## Text messaging

We are currently piloting a new text messaging service. You may be sitting in a hospital waiting room needing reassurance, someone close to you may have just been diagnosed, or you might want to know where your nearest Support Group is and when they're next meeting.

Simply text us on 07786 202030 from your mobile phone. We'll be able to see the previous text messages so you won't need to explain your situation each time you contact us, saving you time. We're sorry but we're unable to receive texts from non-UK mobile numbers. The service is available 9am-5pm Monday to Friday, although you'll still be able to send us messages while we are closed.



*Simply text us on 07786 202030 from your mobile phone.*



Ralph & Jean

### 'Attending a support group made us realise that not only can we cope, but we can enjoy life'

Ralph and Jean were enjoying retirement together when, in August 2015, Ralph was diagnosed with mantle cell lymphoma, a type of non-Hodgkin lymphoma.

Jean explains: 'Ralph was waking up drenched with sweat but kept insisting it was a bug. But when he started to rapidly lose weight, he went to his GP and was referred to hospital. Tests and a scan resulted in a diagnosis of mantle cell lymphoma which was treated with a 6-month course of chemotherapy.

Our clinical nurse specialist suggested we attend the newly-launched Lymphoma Association support group in Colne, Lancashire. Ralph was undergoing treatment and I was worrying all the time about him. I was reassured to meet others at different stages, that were not only coping, but enjoying life. We have made many friends at the group and picked up lots of hints and tips, like pacing yourself. We were worried about going on holiday but, with encouragement from others in the group, we went away. We had a really enjoyable time and at 78 and 74 we're doing far more than we used to. The groups are so helpful and it's reassuring to have so much support from the Lymphoma Association.'

*Jean*

## **Congratulations to the Norfolk Lymphoma Group for putting on an absolutely fantastic fundraising event in July at the Bishop's House Garden, Norwich, raising more than £3,000 for the Lymphoma Association.**

Activities at the event, which was attended by the Lord Mayor, included giant-sized children's games, a treasure trail, live music and Morris dancing.

Our grateful thanks to everyone involved in this successful event and for their unfailing commitment to supporting people

affected by lymphatic cancer.

The Norfolk Lymphoma Group (NLG) meets informally every other month in Norwich with the aim of raising funds for the Lymphoma Association and awareness of the disease. They have raised nearly £160,000 since the group was launched in 2001 by David Cooke, NLG honorary president.

# Bishop's Garden Open day

The Bishop's Garden, in the heart of Norwich, is a private 4-acre garden, which is only open to the public a few afternoons a year. It features an organic kitchen garden, wildflower labyrinth, formal boxed rose garden, and a traditional double herbaceous border.



**Do you have some great ideas to raise money for the Lymphoma Association but need more people to help you get them off the ground?**

**Can we help you set up a fundraising group in your local area?**



Our fundraising groups hold everything from tea breaks, cake sales and golf days, to quiz nights, concerts and street collections – all whilst enjoying great community spirit, learning new skills and making new friends.

There are no rules around the number of events you have to hold and there is no minimum amount you have to raise – every penny counts.

We need as many groups across the country as possible, but they can't exist without you. So please get in touch if you're interested in volunteering to set up or be part of a fundraising group – we can give you lots of help and support!

For an informal chat, call us on 01296 619419 or email us at [fundraising@lymphomas.org.uk](mailto:fundraising@lymphomas.org.uk)

# Conferences

Join us in Lancaster this November for a day that includes talks on the psychological impact of lymphoma, watch and wait, radiotherapy, nutrition, exercise and future treatments for lymphoma.

## Lancaster health and wellbeing day – Saturday 19 November 2016



Save the Date

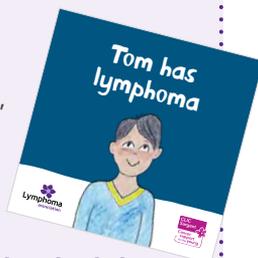
## Lymphoma Association national conference – Saturday 6 May 2017

Save the date for this annual event being held at Whittlebury Hall and Spa, Northamptonshire. To register your interest or sign up to receive an email alert when booking opens, email the education and training team [conferences@lymphomas.org.uk](mailto:conferences@lymphomas.org.uk) or call 01296 619412.

## BMA Patient Information Award for material that shows ‘commitment to responding to needs of patients’

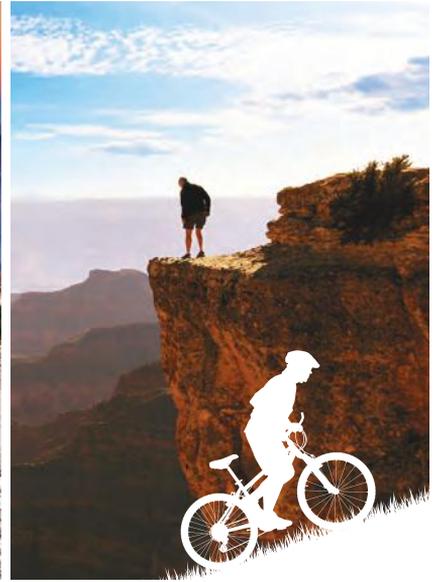
The quality of our information has once again been recognised by the British Medical Association (BMA), the professional body for doctors in the UK. The BMA ‘highly commended’ a mix of material produced by the Lymphoma Association on cancer-related cognitive disorder, or ‘**chemo brain**’. The judges felt the mix of magazine articles, film and web pages were: ‘An excellent resource that serves the dual purpose of offering information and support while also serving as an awareness raising tool about a condition that is not well-understood or researched, but that is clearly pertinent to patients. The fact that the need was identified via calls to the organisation’s helpline shows real commitment to responding to the information needs of patients.’

*Tom has lymphoma*, a storybook produced for children in collaboration with CLIC Sargent, was ‘commended’ by the BMA. They said the book is a ‘very clear readable publication with the right level and language.’



*Tom has lymphoma* can be ordered or downloaded at [www.lymphomas.org.uk/Tom](http://www.lymphomas.org.uk/Tom) and information on ‘chemo brain’ at [www.lymphomas.org.uk/ChemoBrain](http://www.lymphomas.org.uk/ChemoBrain). Alternatively call us on 0808 808 5555 for copies.

**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](http://www.lymphomas.org.uk/MedicalPanel)



Las Vegas **Cycle Ride**  
OCTOBER 2017



This incredible Grand Canyon to Las Vegas cycle ride will take you on a journey starting at the ancestral lands of the Native American Navajo Nation in the iconic Grand Canyon – one of the Seven Natural Wonders of the World.

Cycling through high desert, canyon rims and unforgettable landmarks you will ride through parts of the famous Route 66 highway, finishing in the spectacular city of Las Vegas. This amazing challenge allows you to immerse yourself in the Wild West frontier and experience the glitz and glamour of the famous Las Vegas strip. For more details visit [www.lymphomas.org.uk/GrandCanyonLasVegas](http://www.lymphomas.org.uk/GrandCanyonLasVegas) or call **01296 619419**.

# Lymphoma

A clinical trials  
information  
service



Finding clinical  
trials just got  
easier.

[www.lymphomas.org.uk/TrialsLink](http://www.lymphomas.org.uk/TrialsLink)

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T-cell skin lymphoma  
non Hodgkin lymphoma  
Diffuse large B-cell lymphoma  
Vascular large B-cell lymphoma  
Primary mediastinal large B-cell lymphoma  
Burkitt lymphoma  
Mantle cell lymphoma  
Primary central nervous system lymphoma (slow-growing) B-cell lymphoma  
Follicular lymphoma  
Lymphoma (Waldenström's macroglobulinemia)  
T-cell lymphoma  
Peripheral T cell lymphoma  
Chronic lymphocytic leukemia  
Classical Hodgkin lymphoma  
B-cell skin lymphoma  
Post-transplant lymphoproliferative disorder

Lymphoma Association  
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Aylesbury, Bucks HP20 2PB  
[www.lymphomas.org.uk](http://www.lymphomas.org.uk)  
Freephone helpline 0808 808 5555

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or telephone 01296 619400.

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

- Visit [www.lymphomas.org.uk/donate](http://www.lymphomas.org.uk/donate)
- Text LAUK02 and the amount  
you'd like to donate,  
eg LAUK02 £30, to 70070
- Call us on 01296 619419.

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**Lymphoma**  
association

