

lymphoma

MATTERS

ISSUE 110 | SPRING 2018

WELCOME
TO Fabulous
LAS VEGAS
NEVADA



FOCUS

Skin lymphoma
Clinical trials update
Exercise



Lymphoma
association



Image: stock photo of pharmacist

06 Understanding skin lymphoma



16 Beacons of Hope Awards



20 Christine's follicular lymphoma reappears



30 Exercise and lymphoma



35 Conferences

Contents

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.

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

© Lymphoma Association 2018. For further information about permitted use of our materials, please refer to our website.

Cover: John and Maria renew their vows in Las Vegas after John's Hodgkin lymphoma diagnosis and treatment.

Editor: Anne Hook

04 Latest news

Update on lymphoma and the Lymphoma Association

12 Clinical trials

Updates from clinical studies group

15 Anthony's story

The challenge of a skin lymphoma diagnosis

19 Waldenström's macroglobulinaemia

New registry developed and drug update

23 Ask the experts

Radiotherapy and proton beam therapy

32 Support group update

What's happening in your area?



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





Jonathan Pearce
Chief Executive

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

Updates from the American Society of Hematology (ASH) meeting and their implications for clinical practice in the UK are available at www.lymphomas.org.uk/News



We hope you like our magazine. If you haven't already done so, don't forget to opt-in to receive future issues at www.lymphomas.org.uk/LMOptin

Changes

I write this editorial with mixed feelings, as I will shortly be leaving the Lymphoma Association to take up a European role with the Lymphoma Coalition. It has been a pleasure and privilege to have led the charity for the last four and more years. I'm proud of what we have achieved in that time, while also eagerly anticipating what is to come in the future, including a new name and brand (see below), along with the launch of an exciting new website.

Helping and supporting people affected by lymphoma is not as widely acknowledged and recognised as it should be. I have learned this first hand from the many people who use the charity's services and support its work. That makes the work of the Lymphoma Association even more important than ever.

Over the last four years we've taken great strides forward in reaching many more people affected by the life-changing nature of a lymphoma diagnosis and in providing more and better information and services for them, including our *Live Your Life* survivorship programme, *Lymphoma TrialsLink* and a range of education events, to name but a few new initiatives. All of this we've done through modernising how the charity works, involving those we're closest to much more in what we do, and through working with an ambition to achieve more for the people we're trying to help. I'm confident that the charity will go from strength to strength in the years ahead and I look forward to seeing those achievements.

Coming soon... Spring is a time for cleansing and refreshing! We'll be launching an updated name and look to make our voice louder and stronger, so that more people affected by lymphoma know about us and can get the help and support they need. Our high-quality information and support services will not change. However, this is an incredibly important step in ensuring that we remain a charity solely dedicated to people affected by lymphoma, informing, supporting and connecting them to each other, so that no-one is left to face their lymphoma alone.

Look out for more information about this updated look on our website and in the next edition of *Lymphoma Matters*.





Grant set to benefit 18-30 year olds with lymphoma

Young people across the UK now have a *Live your Life* workshop aimed at their age group, thanks to the BUPA UK Foundation.

Over the next 18 months, we will hold young people's *Live your Life* workshops around the UK for 18-30 year olds who have been diagnosed with lymphoma. The workshops are designed to help young people manage their physical and mental wellbeing immediately after treatment and in the longer-term.

Each of the one-day workshops, which are an extension of our existing *Live your Life* survivorship programme, will be facilitated by a young person who has had lymphoma.

Live your Life project coordinator Rachel Blackford said: 'I'm really excited to be involved in facilitating these workshops. Having been diagnosed with lymphoma when I was 13, I know how

difficult it is to get back into 'normal' life and it will be great to help others navigate this difficult, and often isolating, time.' Topics covered

in the workshops include returning to work or university after treatment, fertility and relationships, and the emotional impact of cancer.

Parliamentary blood cancer report published

The All Party Parliamentary Group on Blood Cancer has published its first report *The 'Hidden' Cancer – The need to improve blood cancer care*.

It follows an inquiry into blood cancer care in the NHS and incorporates evidence provided by a range of sources including charities, clinicians, and patients. The inquiry focused on all aspects of blood cancer, including awareness, diagnosis, patient experience, commissioning of services and clinical research.

The report states that while the Government's England Cancer Strategy is striving to improve patient experience and outcomes, the specific needs of blood cancer patients are not being met.

Furthermore, it reports that the experience of blood cancer patients is different to that of solid tumour cancer patients and, consequently, general cancer services are not always effective in meeting blood cancer patients' needs.

The report goes on to make recommendations on how to improve patient experiences and outcomes for blood cancer patients and calls on the Government and the NHS to ensure that blood cancer and the needs of blood cancer patients are addressed.

Read our full statement online at www.lymphomas.org.uk/BloodCancerReport

Mixed opinions at Britain Against Cancer Conference

The progress of the Government's cancer strategy for England (entitled *Achieving World-Class Cancer Outcomes*) was the topic of the 2017 Britain Against Cancer Conference (BAC).

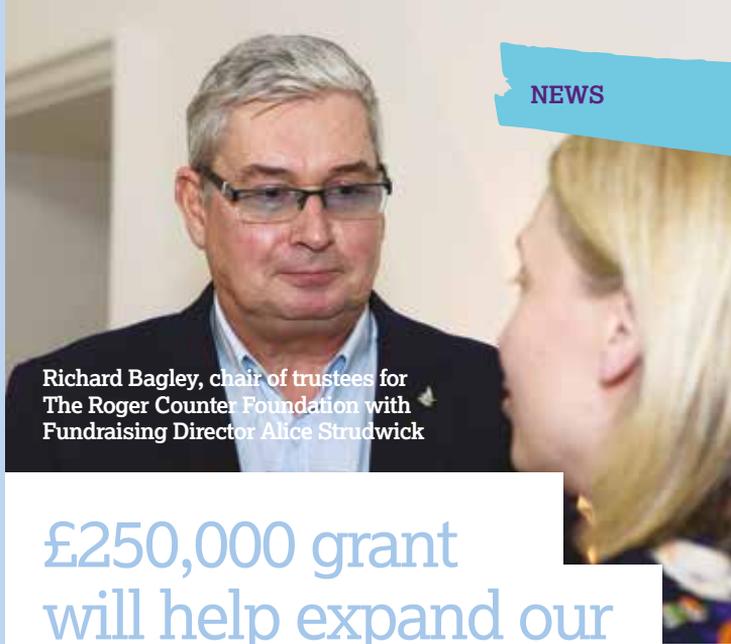
The annual conference, in its 19th year, brings together the cancer community, including health professionals, patients, charities, NHS, and private sector representatives to discuss, learn, and exchange ideas to ensure that cancer outcomes continue to improve.

Delegates, panel members and guest speakers were invited to explore the findings and recommendations of the All Party Parliamentary Group on Cancer (APPGC) inquiry, which reported on the progress made since the publication of the England Cancer Strategy in 2015.

The APPGC report highlights areas of concern, including low survival rates, workforce issues and early diagnosis, where implementation of the strategy is failing to meet its objectives.

Secretary of State for Health and Social Care Jeremy Hunt MP, Shadow Secretary of State for Health Jonathan Ashworth MP, NHS National Cancer Director Cally Palmer, patient representative Fiona Carey and journalist and patient Nick Robinson all presented their thoughts on the progress of the cancer strategy, as did members of an expert panel.

Erika Murigi, our PR and public affairs manager, who attended the event, said: 'The England Cancer Strategy is nearing the half way stage and the conference highlighted some of the mixed opinions on whether it is meeting its objectives. While it's clear there is still much work to be done to see the strategy fulfilled, it's encouraging that there is such a wide range of stakeholders committed to improving cancer outcomes in England.'



Richard Bagley, chair of trustees for The Roger Counter Foundation with Fundraising Director Alice Strudwick

£250,000 grant will help expand our work across the UK

Charitable trust The Roger Counter Foundation has marked its 10th anniversary by awarding us a grant of £250,000 so we can reach even more people affected by lymphoma in the UK.

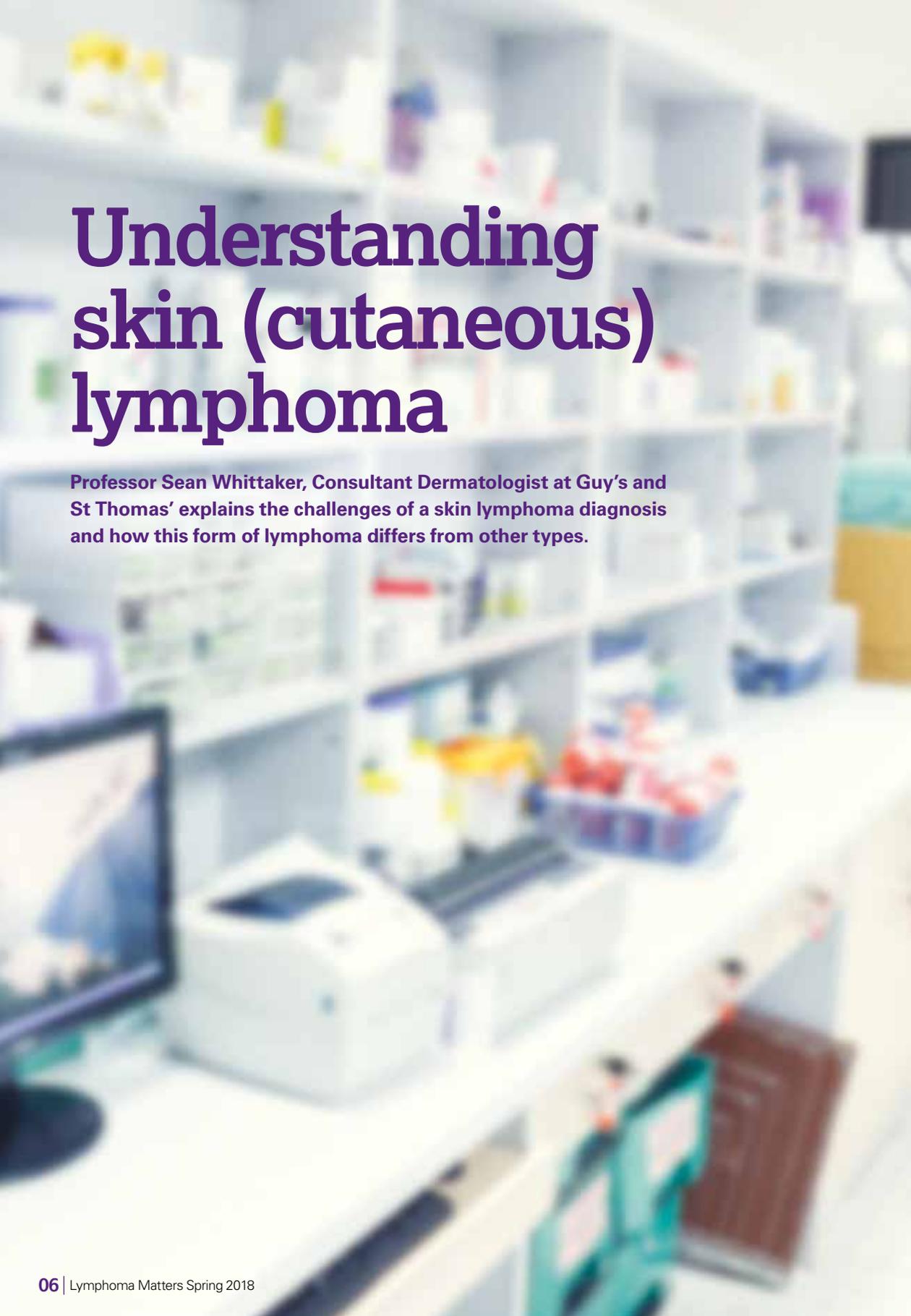
As well as helping to fund core services like our support group network and buddy scheme, the grant will help us expand our regional networks so that more people can access our information and support services locally.

The Foundation was set up in 2007 by Roger Counter, a Bournemouth property developer, who had been diagnosed with Burkitt's lymphoma in 2006.

Richard Bagley, chair of trustees for the Foundation, said: 'Roger desperately wanted to understand lymphoma and one of our aims is to make sure that people affected get the best information and support to give them the knowledge and strength to face this complex cancer.'

Jonathan Pearce, our chief executive, said: 'We are immensely grateful to the Roger Counter Foundation for supporting our work for many years and for this exceptional grant. We thank the trustees for their ongoing support and generosity.'

Go to www.lymphomas.org.uk/supportgroups to see what's happening in your area.



Understanding skin (cutaneous) lymphoma

Professor Sean Whittaker, Consultant Dermatologist at Guy's and St Thomas' explains the challenges of a skin lymphoma diagnosis and how this form of lymphoma differs from other types.

What is skin lymphoma?

Lymphoma is a cancer that starts in cells called lymphocytes, which are part of the immune system. Lymphocytes are normally found in the lymph nodes and blood. They are also found in other lymphoid tissues, for example, in the spleen, the gut and the skin.

If lymphocytes start to grow out of control, or don't die after their normal lifespan, they can build up and form a cancerous collection of cells. This is a lymphoma. If the lymphoma starts in the lymphocytes in the skin, it is called a 'cutaneous' lymphoma, which means a lymphoma 'of the skin'.

Cutaneous or skin lymphoma is a type of non-Hodgkin lymphoma (NHL). Like other types of NHL, it may be high-grade or low-grade and B- or T-cell types. The most common skin lymphoma is a low-grade T-cell type called mycosis fungoides (MF).

There are two types of lymphocytes: B lymphocytes or B cells and T lymphocytes or T cells. With most lymphomas, it is more common for the lymphoma to originate in the B cell. However, with skin lymphoma it is more common in T cells as these are more common outside the lymph gland tissue, including in the skin.

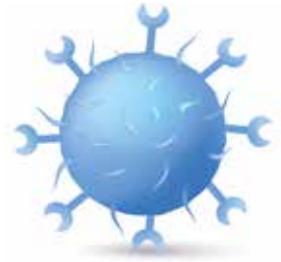
The skin is our largest organ and accounts for 12-15% of total body weight. There are about 20 billion T cells in human skin – far more than in the blood. Although most immune cells do not live a long time, over 95% of the T cells in skin are memory T cells, meaning they remember the various diseases, especially infections, and are therefore poised to rapidly respond again.

How common is skin lymphoma?

Skin lymphoma is a rare condition. About 1 in 100,000 people are newly diagnosed each year. However, this may be an underestimate as people may think they have another skin condition and not report it to their doctor.

How is skin lymphoma diagnosed?

It is not uncommon for 2-3 years to go by after symptoms start before an accurate diagnosis of a skin lymphoma. This is because some of the symptoms of skin lymphoma (dry, sometimes scaly skin that can be itchy or form a rash) are very similar to those of other, more common conditions, such as eczema or psoriasis.



An illustration of a T-cell



Did you know?

Skin lymphoma and cutaneous lymphoma are different names for the same condition. Your health team may talk about cutaneous T-cell or cutaneous B-cell lymphoma.

‘Friends and relatives ask for an explanation of the disease – that’s easier said than done with such a complicated disease.’ *John*

As skin lymphoma is a rare condition, GPs typically only see one or two cases in their career. They are therefore likely to rule out other skin conditions first.

People worry about a delayed diagnosis, but for most people with skin lymphoma, it is unlikely to affect the outcome.

‘My skin condition has been around since 1972, but it has only been recently that I have been told it is a cancer.’

Staging of skin lymphoma is different from other lymphomas

Skin lymphoma is staged in a different way to other

lymphomas, such as follicular or diffuse large B-cell. This is because staging measures the amount of skin affected by the disease.

- ✓ **Stage IA** (or early stage disease) – patches cover less than 10% of your skin. To put it in perspective, a person’s palm amounts to around 0.4% of their skin areas, so 10% of skin would roughly be both arms.
- ✓ **Stage IB** – more than 10% of the skin is affected by plaques and patches.
- ✓ **Stage IIB** – tumours are present on the skin.
- ✓ **Stage III** – 90% or more of the skin is affected, this is known as erythroderma.
- ✓ **Stage IV** – lymph gland and/or internal organ involvement.

What are the treatments for skin lymphoma?

Like other types of lymphoma, many people with a slow-growing skin lymphoma don’t need treatment straight away. Instead, a period of monitoring known as ‘watch and wait’, is often used for early stage disease. Research and many years of experience have shown that this is the best approach for some types and stages of skin lymphoma.

‘Coping with the symptoms is very individual. It feels very much like my unique disease.’

'I'm on 'watch and wait', but what am I waiting for?'

The name 'watch and wait' suggests that something is going to happen. 'Watch and wait' is a common form of treatment for low-grade lymphoma, where people are regularly monitored. In many ways, monitoring skin lymphoma is easier than other types because you can visibly judge if the condition is progressing.

If your consultant feels that treatment would help, several options are available. The treatment recommended depends on the type of skin lymphoma and how much of the body is affected.

'Watch and wait' is a common form of treatment for low-grade lymphoma

The two types of treatment used are those applied directly to affected skin (skin-directed treatments) and those given to the whole body (systemic treatments).

Skin-directed treatments include steroid creams and ointments, chemotherapy lotions, radiotherapy, including total skin electron beam (TSEB) therapy, and ultraviolet light treatment, either UVB or PUVA.

PUVA involves use of the drug psoralen (P) to sensitize the skin, which is then treated with long wavelength ultraviolet light (UVA). PUVA can be very effective, but

Tips on coping with a skin condition

With thanks to Ashley of the charity Skinship (skinshipuk.org, helpline number 01557 428504) and members of the Skin Lymphoma Discussion Group in London for providing us with these helpful tips.

Don't get too hot

Heat irritates the skin.

Baths and showers

Try a body-temperature shower or bath rather than a hot one. It really helps. It might not be so enjoyable, but hot water drives the naturally moisturising sebaceous oils out of the skin.

Soaps and shampoos

Soaps, shower gels and shampoos also wash natural oils out of the skin, which are then often replaced by costly moisturisers. People who don't use shampoos or conditioners, but who wash their hair with warm water, often have the best hair and cleanest scalps.

Drying your skin

Pat or dab your skin dry with a clean towel to avoid irritation. If you need to use moisturiser, apply it while your skin is still slightly damp, as this will help lock the moisture in.

Washing clothes

Washing machines now use less water, which is excellent news environmentally. But the result is that detergent can remain on the clothes. After normal washing, put your clothes through a separate rinse cycle to get rid of any soap residues..

Choose clothes that don't irritate

If you wear wool, don't have it next to your skin as it can irritate. Cotton and bamboo fabrics can feel good against your skin.

'Certain materials aggravate. Cotton is the kindest one for me and bamboo is really good. I got a couple of vests made from bamboo which were fantastic.'

John

Trying to break the itch-scratch cycle

Avoiding scratching is easier said than done. However, individual itches don't tend to last, so sitting on your hands and counting to 30 should mean that the itch has gone; you haven't scratched and therefore haven't damaged the skin and made it more itchy.

Your medical team

This is a rare disease, which falls between the specialities of dermatology, oncology and haematology. Don't be afraid to ask the consultant about their experience in dealing with skin lymphoma.

'I really value the support group, and it helps to know you are not alone with this disease.'

there is a lifetime limit to the light treatment a person can have. As a result, medical teams measure the total cumulative dosage, being careful not to go over the maximum amount.

There is a wide variety of medications reported to help with the itching associated with skin lymphoma, but many only have a partial effect. A large number of creams are available and finding what works is really a case of trial and error. What suits one person does not necessarily suit another. If something is effective, but the effect has worn off after some time, then it may be worth trying it again after a break.

Systemic treatments include steroid tablets, chemotherapy and a range of biologic therapies such as alpha interferon and bexarotene. Now that NICE recommends rituximab for stage 3 or 4 follicular lymphoma, it can be used for

people with extensive B-cell but not T-cell lymphomas.

A stem cell transplant can be used in the treatment of people with advanced cutaneous lymphoma. This is a complicated procedure and in the first year there is a high risk of complications. For more information about stem cell transplants, go to www.lymphomas.org.uk/SCT.

Are there any clinical trials for skin lymphoma?

There are very few trials for skin lymphoma and most are for cutaneous T-cell types such as mycosis fungoides or Sézary syndrome at an advanced stage, where options are more limited. Different trials have different eligibility criteria, but if you are interested in taking part in a clinical trial, speak to your medical team to see if one may be suitable for you.

> Commonly asked questions

Is skin lymphoma connected to sun exposure?

There is no evidence that sun is connected with skin lymphoma, but there are investigations to try to qualify that. In fact, we often find that patches and plaques appear where there is less light on the body, such as the shoulder or pelvic area.

Is skin lymphoma associated with other medical conditions, such as asthma or diabetes for example?

Skin lymphoma is not known to be associated with any other medical conditions.

Like everyone else, you should use sun screens.

- Skin lymphoma is a rare form of skin cancer. It has several types but is usually very slow growing. It can take many years or even decades to become troublesome.
- Skin lymphomas are often very difficult to diagnose as they look similar to much more common skin conditions such as eczema and psoriasis.
- The most common skin lymphoma is mycosis fungoides or MF. It is not known what causes MF.
- Skin lymphomas are not considered to be curable, but they are slow growing and respond well to treatment. This means that the skin problems come and go and need treatment only some of the time.
- Having a skin lymphoma does not usually affect your life expectancy.
- There are several effective treatments, including steroid creams, light treatments (such as PUVA), radiotherapy, chemotherapy and biologic drugs like bexarotene and alpha interferon.

IN
BRIEF

More of a historical novel

Tony explains the challenges of getting a skin lymphoma diagnosis

'In 2001, with a little help from an article in the Lymphoma Association's magazine, I finally thought I had discovered the name of the skin condition I had been living with – cutaneous B-cell lymphoma.

To put things into context, in 1985 I consulted my GP about some itchy lumps on my upper arms. He dismissed them as nothing more than fatty tissue. The following year, I was referred to my local hospital where the lumps were cut out and sent for analysis. My next hospital appointment was with an oncologist who acknowledged that I had cancer – a low grade non-Hodgkin Lymphoma.

I had never heard of lymphoma, high-grade or low-grade, Hodgkin or non-Hodgkin and in that era it wasn't very easy to get information. I was in my mid-forties, with a wife and two teenage sons. I had a lot of worry.

The rest of the period up to 2001 became a round of radiotherapy, X-rays, CT scans and more minor surgery to remove cancerous lumps. During this period I became more and more frustrated as I still did not have an accurate diagnosis. On a Lymphoma Association bike ride I met many other people with lymphoma who could not only quote me chapter and verse of their precise diagnosis but also the stage they were at. All I knew was that I had a low grade non-Hodgkin lymphoma.

During this period I took early retirement. My ill-defined lymphoma was a factor in my decision, although in all honesty I'd had enough of a very stressful job as a finance director involved in implementing poll tax at a local level.

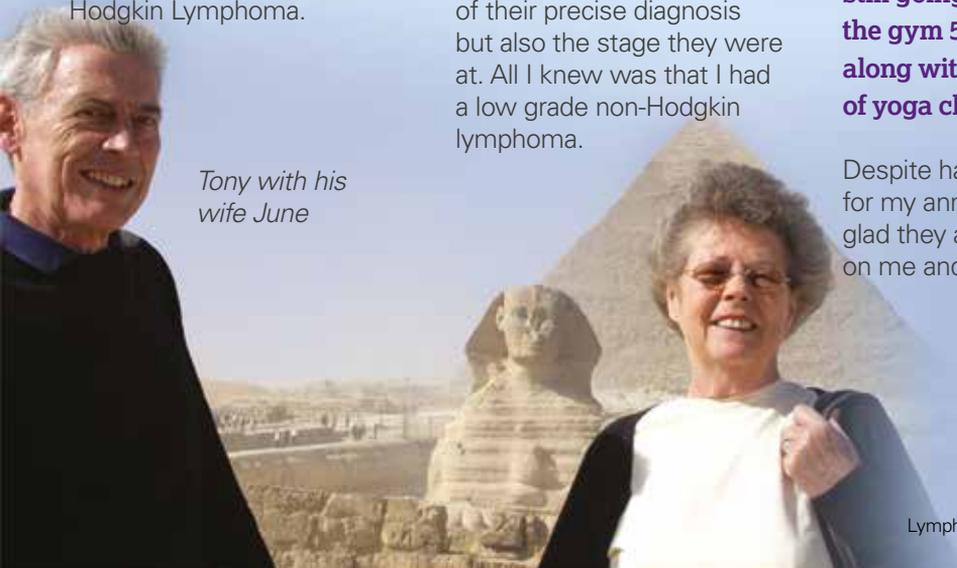
I was eventually referred to a professor who listened carefully to what I had to say and said that he was inclined to agree with my diagnosis but would carry out further tests before committing himself. While I was there, one of his team removed a lump that had re-grown and took some blood. I went back a few days later for a bone marrow biopsy. After confirmation of the diagnosis at my next appointment, I was introduced to other members of his team including the senior radiologist who was on the phone to me as soon as I got home with dates for my treatment.

Over 30 years later, I am still going strong, going to the gym 5 days a week, along with doing a couple of yoga classes. I feel lucky.

Despite having a bit of a trek for my annual check-up, I'm glad they are still keeping tabs on me and my skin lymphoma.'

Tony with his wife June

Tony





Report from the
National Cancer
Research Institute
(NCRI) Lymphoma
Clinical Studies
Group

Update on clinical trials

Clinical trials are vital to answer key questions about lymphoma and its treatment. In rare diseases like lymphoma, it is particularly important that researchers collaborate to identify these key questions and to find the best way to answer them.

The National Cancer Research Institute (NCRI) is a partnership between organisations that fund cancer research in the UK. **The Lymphoma Clinical Studies Group** (part of the NCRI) holds an annual meeting in November each

year to discuss current trials and gather input on plans for new trials.

Hodgkin lymphoma

Most people respond very well to treatment for Hodgkin lymphoma but there are still people for whom the

standard treatment of ABVD chemotherapy does not work well.

Brentuximab vedotin is a newer drug used to treat some people who do not respond to standard treatment and trials are

underway or being planned to test whether this drug could also make standard treatment more effective if used as part of first-line treatment. The aim of these trials is to increase the number of people who respond to treatment and decrease the need for radiotherapy.

Previous studies have shown that omitting radiotherapy from the treatment plan for people who respond well to chemotherapy still gives good outcomes but slightly more people relapse (their lymphoma comes back) after treatment. Making first-line treatment more effective could mean that even fewer people need radiotherapy.

Radiotherapy and chemotherapy can both cause late effects – health problems that appear months or years after treatment. There is continuing work to try to reduce long-term problems by reducing radiotherapy and by incorporating newer drugs into first-line treatment.

Researchers would also like to find out whether PET scans done earlier in the treatment course can help predict who will respond to their treatment, and could therefore increase their chance of a good outcome by indicating a need to change their treatment earlier.

Trials for people with Hodgkin lymphoma that doesn't respond to first-line treatment or relapses are focusing mainly on newer drugs, such as checkpoint inhibitors (eg nivolumab) and brentuximab vedotin.

High-grade non-Hodgkin lymphoma

Chemotherapy is still a very important part of treatment for high-grade (fast-growing) non-Hodgkin lymphoma (NHL).

- ✓ The **HOVON** Burkitt trial is comparing two different chemotherapy regimens (combinations of drugs) for **Burkitt lymphoma**.
- ✓ Newer regimens are being tested in clinical trials for relapsed **primary central nervous system (CNS) lymphoma** (the TIER regimen) and for **secondary CNS lymphoma (MATRIX with R-ICE)**.

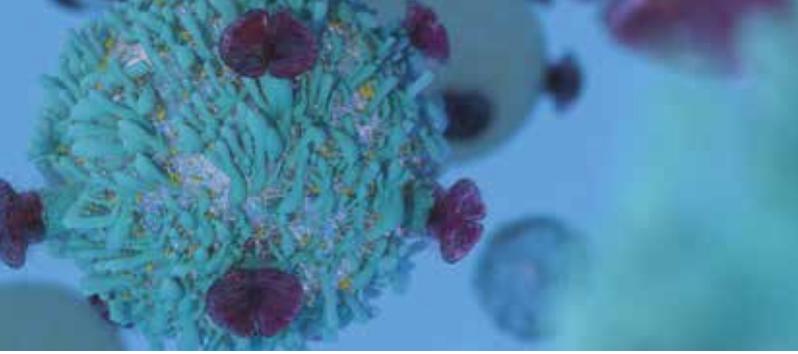
Newer drugs

Lots of studies are trying to improve outcomes for people with high-grade NHL using newer drugs. Combinations of newer drugs could be particularly helpful for people who are not able to have stronger treatment. They could also help some people avoid the side effects of more intensive treatment and offer treatment options for people who relapse or don't respond

to standard treatment. Rituximab alone can sometimes control **post-transplant lymphoproliferative disorder (PTLD)** – an accumulation of lymphocytes or a lymphoma that can happen after an organ transplant or an allogeneic stem cell transplant. However, many people need more intensive treatment. **TIDaL** is testing whether the combination of rituximab and ibrutinib could mean that fewer people need more intensive treatment. The TIDaL trial should open at most transplant sites in the UK.

ENRICH is the first study to look at a first-line treatment option for **mantle cell lymphoma** that doesn't include chemotherapy. People over 60 who are not suitable for a stem cell transplant could be eligible for this study, which is comparing the newer drugs ibrutinib and rituximab with the standard treatment of rituximab and chemotherapy.

Other newer drugs such as acalabrutinib, inotuzumab and checkpoint inhibitors are being tested in trials to see if they can help improve outcomes for people with high-grade NHL. Acalabrutinib was recently approved for use in the US in people who had already had at least one other treatment for mantle cell lymphoma



following impressive results in a clinical trial.

Targeting change

Biobanks and incorporating genetic testing into trials can give researchers more insight into the biology of lymphoma and how to tailor treatment to the individual.

More than 2,000 people have already been recruited for the **MAPLE** study, which is collecting samples from people with **diffuse large B-cell lymphoma (DLBCL)** to find out more about the genetic changes in lymphoma cells. This information can be used to help guide treatment decisions both now and in the future, as more is learnt about the changes that allow the abnormal cells to grow.

Although the results of the **ReMODL-B** trial showed that adding a newer drug, bortezomib, to standard treatment did not improve outcomes, the trial identified a new subgroup of people with **DLBCL** that was particularly fast-growing. The trial also showed it was possible to find out information about genetic changes in lymphoma cells quickly enough to guide treatment decisions.

A **MCL (mantle cell lymphoma) Biobank** aims to find out what features predict whether MCL will behave in a low-grade manner (grow slowly) instead of the more usual faster-growing type of MCL.

T-cell lymphoma can be challenging to treat as the lymphoma often relapses, and relapsed T-cell lymphoma doesn't usually respond well to chemotherapy. The **T-cell biobank** project is collecting samples to find out more about T-cell lymphoma and how best to treat it.

Low-grade non-Hodgkin lymphoma

Newer drugs are still a key focus for research into treatments for low-grade (slow-growing) NHL and many regimens are being tested in clinical trials. Trials don't exclusively use newer drugs; many trials use a combination of newer drugs and chemotherapy or other existing treatments. For example, the combination of lenalidomide and rituximab is effective for **follicular lymphoma** and the **REBEL trial** will test whether it is safe and effective to add the chemotherapy drug bendamustine to this regimen.

Researchers are also trying to improve quality of life for people with low-grade lymphoma by ensuring that they only get treatment that is needed. The **PETRea trial** is using PET scans to guide treatment decisions for follicular lymphoma. It aims to answer questions about whether rituximab maintenance is needed for people who have a good response to treatment on a PET scan. Although maintenance keeps **follicular lymphoma** under control for longer in some people, it does not affect survival. There are also disadvantages to maintenance, such as a continuing risk of infection. It is important to find out who benefits from maintenance so that those who are unlikely to benefit can avoid unnecessary side effects.

With thanks to Dr Graham Collins, Consultant Haematologist at Oxford University Hospitals NHS Trust and Dr Andy Davies, Consultant in Medical Oncology, Southampton General Hospital for reviewing this.



To find out more

Read clinical trials news stories at www.lymphomas.org.uk/LMTrialsLink, a section of our website dedicated to information about clinical trials. You can search our database to find clinical trials currently open in the UK that might be suitable for you.



Celebrating THE Vinca *(periwinkle)!*

Did you know that the periwinkle flower in our logo is used as an ingredient in some treatments for lymphoma?

Join our love for this humble plant as a symbol of hope and support and help spread awareness of lymphoma by:

- planting some periwinkle seeds and sharing photos of your plants in bloom on social media. Order your periwinkle seeds from our web shop www.lymphomas.org.uk/shop
- wearing a periwinkle badge as a symbol of hope and support for others affected by lymphoma www.lymphomas.org.uk/shop
- crocheting your own periwinkle brooch - whether you are a complete beginner or have years of crocheting experience, anyone can use our pattern* to make this eye-catching periwinkle design www.lymphomas.org.uk/crochet

*with grateful thanks to Lymphoma Lass for giving us permission to use her design



BEACONS OF HOPE Awards

The 2017 Beacons of Hope Awards were held at the stunning Fazeley Studios in Birmingham in November. 19 of the 22 winners joined us for the ceremony, which was compered by BBC Radio 4 presenter, Susan Rae.

Awarded by a group of external judges, including our patron, Lord Menzies Campbell, clinical nurse specialist Barbara von Barsewisch, and chair of the Roger Counter Foundation, Richard Bagley, the Beacons of Hope recognise people who make a difference to others living with lymphoma.



1 Patricia Barnard

Patricia and Kevin Fairbanks (see 4) were nominated for setting up and running the Frodsham support group. Their nominator said: 'Attending the group makes going for difficult treatment so much easier to bear.'

2 Sara Busby

Sara, a senior staff nurse on a young adult cancer day unit, was nominated by a colleague for her commitment to ensuring young adults with lymphoma are well informed, have a smooth treatment pathway and do not feel alone.

3 Clare Ratchford

Clare, a Lymphoma Association buddy, volunteer ambassador, and active

member of the Manchester support group, won an award for her commitment to supporting the Lymphoma Association and others affected by lymphoma.

4 Kevin Fairbanks (see 1)

5 Catherine O'Neill

Catherine nominated the Lymphoma Association as the 2016-17 Charity of the Year for M&S Borehamwood and won an award for her 'never-ending energy and commitment'. The partnership raised more than £7,000 for the Lymphoma Association.

6-9 The staff of Ward T16 South, University College London Hospital

The ward received a nomination praising the 'dedicated and caring' staff for their 'warmth and kindness' and for going 'above and beyond' in their support of patients and their families.

10 Councillor Ali Gul Ozbek

After Cllr Ozbek's brother was diagnosed with lymphoma in 2016 and the family benefited from our services, Cllr Ozbek went on to raise more than £70,000 for the Lymphoma Association during his term as Mayor of Haringey.

11 Theresa Peters

Theresa, a haematology nurse specialist, won her award for her commitment to

setting up and maintaining an active, informative lymphoma support group, all on top of her day job!

12 Michael Burge

Mike continues to offer 'tremendous support and strength' to his wife Sharon after she was diagnosed with lymphoma. He has also supported her to become a Lymphoma Association buddy and advisory group member, and will often accompany her to give talks and presentations about lymphoma.

13 Lymphoma Lass

Lymphoma Lass, an avid knitter and crochet enthusiast, won an award for using her creative skills to raise funds for the Lymphoma Association and awareness of lymphoma. Described as 'totally inspirational', she was said to be 'always cheerful and positive' despite continuing setbacks with her health and ongoing treatment.

14 Jo O'Farrell

Jo, who has lymphoma, received nine nominations from cancer patients who attend the support group she founded in Dorset. She was described as an 'inspiration' having 'changed the lives' of many members and supporting them through their 'darkest of days'.

15 Bianca Snowden-Harris

Bianca, a devoted mother of a young boy, was diagnosed



with Hodgkin lymphoma in April 2016. She was nominated by one of her health professionals who said: 'Bianca faced each consultation and treatment with such a positive attitude, always helping and supporting other patients and inspiring staff on the ward and in clinic.'

16 Eloise Swain

After her father was diagnosed with lymphoma and passed away, Eloise has organised a variety of events to raise awareness of lymphoma and fundraise for the Lymphoma Association, even setting up a dedicated fundraising group in her area.

17 Loraine Derbyshire and the PIU ward, Halton General Hospital. (Pictured is Kate)

Loraine and her team received an award for: 'Their amazing ability to put each patient at ease'. Their nominator wrote that through their 'positive interaction, caring support, and professionalism, people always leave the ward with a smile.'

18 Natalia Bartolomé

Natalia was treated for Hodgkin lymphoma when she was 20 and has remained committed to raising awareness of lymphoma and helping other young people who

have been affected by a lymphoma diagnosis.

19 Sister Vivienne Hayes

Viv is the sister of the Outpatient Department in Cardiff University Hospital. She was nominated for making a real difference to lives of people with lymphoma in Cardiff, having launched the 'Every Contact Counts' campaign.

20 Eleanor Parker

Eleanor, the Ward Clerks for the Haematology Ward at the Vale of Leven Hospital in Alexandria, was described as: 'Such a good ambassador for the Ward and such a good person to have as the first point of contact.'

21 Helen Jarvis

Helen's daughter, Carol, was diagnosed with Hodgkin

lymphoma in 2004. Helen received two nominations for supporting Carol throughout her long illness, including two stem cell transplants, and for helping many other lymphoma patients and carers via an online group for blood cancer patients undergoing stem cell transplants, which she was instrumental in setting up.

Dan Bishop (not pictured as unable to attend)

Dan was treated for lymphoma in 2016 but relapsed the following year. He was nominated for: 'Bringing light and joy into every room' and for continuing to put his family and friends first despite his diagnosis.

Both Eloise and Lymphoma Lass share their experiences at www.lymphomas.org.uk/News

Carol Miller

Owing to mobility issues, Carol was unable to attend the ceremony in Birmingham. So her nominator arranged for her award to be presented at a support group meeting by a consultant haematologist and a group of CNS's from the Magnolia Centre, York Hospital.

Carol received an award for setting up a haematology support group and for going 'beyond the call of duty' for members she knows are struggling with their diagnosis or treatment. Carol also helped set up a buddying system at York Hospital.



Registry for Waldenström's macroglobulinaemia (WM) launched

The Waldenström's Macroglobulinaemia (WM) Registry was set up to capture 'real world' clinical data about WM and closely related conditions in the UK. Routine cancer data typically captures survival rates over a 2-year period. For many lymphomas, this isn't enough, particularly if it's a slow growing non-Hodgkin lymphoma like WM.

Charity WMUK raised funds in memory of the late BBC radio presenter Rory Morrison, to develop a national registry. WMUK polled patients asking if they felt happy at being included. The response was 100% positive – people with rarer diseases welcome sharing their anonymised data for research.

There have been significant advances in recent years in the understanding of WM genetics and treatment. The Registry aims to understand the impact that novel

therapies are having, not only on patients' survival and comorbidities, but also their quality of life. It aims to monitor **the whole patient pathway including complications and outcomes**, specifically relevant to WM and related conditions and includes patient reported data.

Eleven hospitals are involved, with over 400 people already on the Registry. For the first time, NICE agreed to consider this data when making future decisions on ibrutinib, a drug currently available on the Cancer Drugs Fund, and this created a pathway for future drug approvals for WM. If your hospital is not included, ask your consultant if they will join. More details can be found at www.wmuk.org.uk

Roger Brown, Chair of WMUK, comments: 'For rarer diseases like WM, this will provide a greater insight into quality of life and treatment effectiveness, aiding treatment decisions in the future.'

Concern over bendamustine availability

There is concern that bendamustine may not continue to be funded as a widely used first treatment in WM (usually in combination with rituximab) and some other non-Hodgkin lymphomas. It has been shown to be very cost-effective, with the advantage of minimal hair loss and being able to continue working while receiving it.

Bendamustine is available via the Cancer Drugs Fund, meaning they are evaluated by NHS Specialised Commissioning, not NICE, and thus subject to competitive funding against other treatments when considered for permanent use. Last December it rejected it on cost grounds. If not approved in 2018, it will be permanently removed. WMUK are currently campaigning with blood cancer charities to reverse this decision.

To find out more, visit
www.wmuk.org.uk



Follicular lymphoma reappears

For several months during 2000 I was feeling more tired than usual, but put it down to quite a heavy workload. I was kept busy with three children, mostly grown up and at university, but one teenager still at home, and working a 28-hour week as a medical secretary in a nearby hospital.

Christine

I noticed I was becoming increasingly breathless when walking our golden retriever dog and then found a lump in my neck below my chin. I decided to visit my GP.

Initially I was told the tiredness might be my age (then 54) but after two further visits to the surgery, the GP measured the lump in my neck and decided it was getting bigger. A referral to an ear, nose and throat (ENT) consultant swiftly followed and a needle biopsy proved inconclusive. So I was admitted to hospital to have the lump removed under a general anaesthetic, along with some saliva glands. This was all sent off for further analysis.

In July 2000 I was diagnosed with low-grade follicular non-Hodgkin lymphoma, stage 3 and referred on to an oncology consultant. CT scans had revealed some suspect lymph nodes in both sides of my abdomen. It was decided I should receive a six-month course of chlorambucil, a type of chemotherapy given in tablet form. This entailed very regular visits to the oncology clinic to check blood results. Unfortunately, due to a low white cell count and neutrophils, I was not able to complete the full course of six months. The fortnightly dose of tablets was cut to 10 days and the full six-month course was cut down to five months.

By 2002 I felt increasingly better with more energy and had returned to work. I found that gardening, walking, sailing and cycling helped to keep me fit. I felt good for a number of years and my regular visits to the oncology clinic were eventually reduced to yearly.

In the spring of 2016 I noticed I was developing a drooping right eyelid. This progressed over the months and I found I was having to literally hold and pull it up in the evenings if I wanted to watch TV or read. I paid a visit to the optician who found nothing wrong and said my sight hadn't deteriorated.

The eyelid got worse. My family commented on it and my youngest daughter, Sophie, noticed I had developed a small oval shaped lump to the outer edge of the eyelid. This became quite prominent and I found I was unable to use eyeliner over the lump. I went back to the optician, who was more concerned with the drooping eyelid than the lump and suggested I visit my GP. At this point I didn't suspect lymphoma, so did not contact the oncology department.



Did you know?

Follicular lymphoma is the most common type of low-grade non-Hodgkin lymphoma. It grows very slowly and often has few symptoms or none at all. Most people are at an advanced-stage when they are diagnosed.

After my visit to the GP I was referred to an eye surgeon for a possible corrective 'cosmetic' job to the eyelid. The surgeon felt that the drooping eye-lid was probably an age-related problem (I was now 70 years old), and that the lump might be a prolapsed lacrimal gland (the tear gland). However, while he applied for NHS approval to perform 'cosmetic' surgery to the eyelid, he arranged a CT scan. This showed a suspicious lump retreating behind the eye socket. So I



'I count myself fortunate to have pootled along happily for sixteen years and am hoping for many more!'

was back in for day surgery for a biopsy.

The following day, I developed a lovely boxer's black-purple eye and swollen cheek. Nevertheless, a week later I went on a pre-arranged holiday to France with my husband, with advice from the surgeon not to swim because of possible infection.

On our return the surgeon informed me that the lump was a lymphoma of the lacrimal (tear) gland, which is quite rare.

I was referred back to the oncology team, and a daily 12-day course of radiotherapy was arranged. I was invited

to the hospital to view the treatment room and meet the staff. It was decided that I would not require a face mask; instead I would wear a lead eye shield in my right eye whilst receiving the radiotherapy. A tracing of the right side of my face and eye was taken, which was used each time to mark out the area around the eye to be treated.

The type of radiotherapy used is known as orthovoltage X-ray treatment. The X-rays produced by the orthovoltage X-ray tubes do not penetrate deep into the body, so are useful in treating shallow tumours. The treatment involved lying on the bed,

having anaesthetising drops inserted into the right eye and then a small lead eye shield (over the pupil area) inserted. I found this rather fiddly and slightly uncomfortable, but the staff were first class and minimised the discomfort. The unit itself was pulled down from the ceiling and the arm of the unit placed on the marked area on the side of my temple. I then had to keep very still for a few minutes while the radiographers disappeared behind a screen and pressed the button. I was not allowed to drive for 4–5 hours after each treatment so my husband became my chauffeur.

I returned to the oncology clinic for several check-ups and have now been extended to a six-month review. I am really pleased with the outcome and fingers crossed the lump won't return. I have been advised that if it does return I will not be able to have more radiotherapy, but alternative treatments would be looked into.

I am due to see the 'cosmetic' eye surgeon, but I already know that I will not be requiring the eyelid lift! As he told me on my last visit, it was the weight of the tumour that was dragging the eyelid down.

When I am tired (fairly often with three young active grandchildren visiting regularly) my eye feels and looks droopy, a little like a 'lazy' eye, but otherwise I have no after effects and no problems. I count myself fortunate to have pootled along happily for sixteen years and am hoping for many more!

Christine



Did you know?

Follicular lymphoma is uncommon under the age of 50, but can affect people of any age. Updated information about follicular lymphoma is available at www.lymphomas.org.uk/FL



ask the expert

➤ **Christine needed radiotherapy to the eye for a relapsed follicular lymphoma using orthovoltage X-ray treatment. Is this widely used?**

Radiotherapy is a very effective treatment for follicular lymphoma, and a trial in the UK showed that even low doses, for example two treatments, can shrink lymphoma with very few side effects.

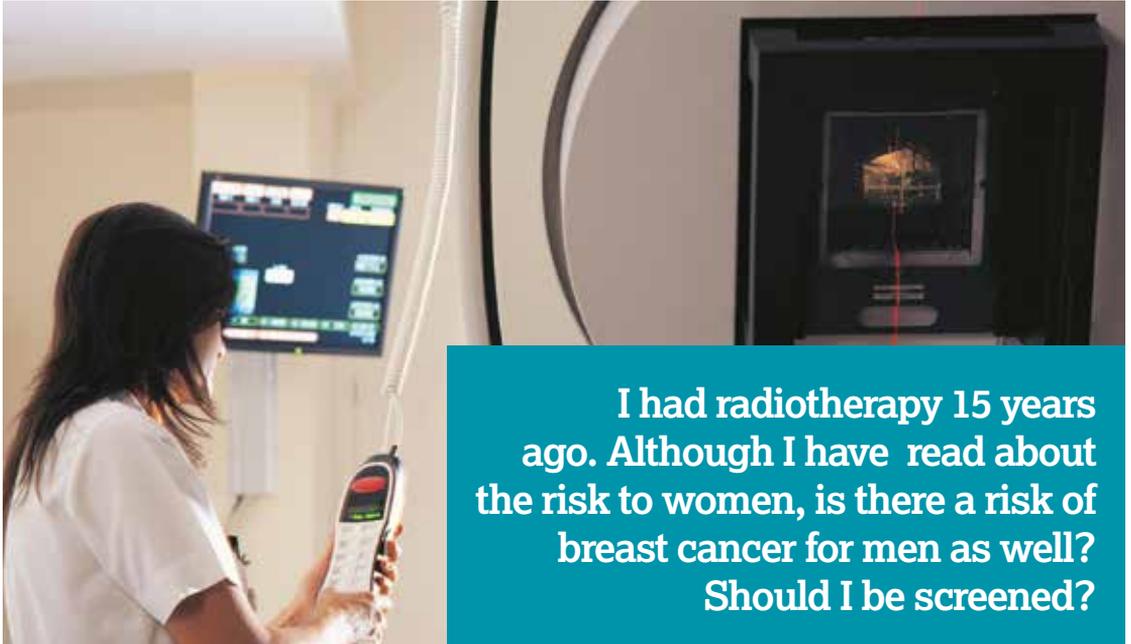
Radiotherapy treatments are designed to target the tumour and spare as much surrounding normal tissue as possible. Superficial or orthovoltage X-rays are strong enough to kill cancer cells but do not penetrate more than a few millimeters beyond the surface of the skin. The applicator of the machine, through which the X-rays are delivered, is brought very close to the area being treated. It can take 5-10 minutes for each treatment. The machine is very different from the large linear accelerators that deliver high energy or megavoltage radiotherapy. Superficial and orthovoltage X-rays are used in many radiotherapy departments for the treatment of superficial skin cancers or lymphoma and for tumours close to the surface of the body such as around the front of the eye.

You can read more about radiotherapy at www.lymphomas.org.uk/Radiotherapy

**READ
MORE**

With thanks to Dr Eve Gallop-Evans, Clinical Oncologist, Velindre Hospital, Cardiff for answering this questions and those on pages 24 and 25.





I had radiotherapy 15 years ago. Although I have read about the risk to women, is there a risk of breast cancer for men as well? Should I be screened?

Radiotherapy, while an important treatment for cancer, can also cause changes in normal cells which, over many years, can become cancerous. Radiotherapy to the chest area can increase the long-term risk of getting breast cancer. This risk is highest for girls and young women treated around the time of puberty or shortly after, when breast tissue is actively growing. The risk is higher if more breast tissue is treated, or if higher radiotherapy doses are used.

Advances in treatment have led to more targeted radiotherapy, irradiating less of the normal tissue and using lower radiotherapy doses. Women who have had radiotherapy to the chest area under the age of 36 years are referred for breast screening eight years after radiotherapy. They have annual mammograms or MRI scans until the age of 50, when they go into the standard three-yearly screening programme.

The risk of breast cancer in men is lower as men have much less breast tissue than women. There is no evidence that breast screening is effective in men so this is not offered routinely. The most common sign of breast cancer in men is a painless lump. These changes are easier to notice in men than in women. For men and women, any change in the breast (or chest area) or nipple can be a warning sign of breast cancer, and you are advised to see your doctor as soon as possible. These symptoms may also be signs of a benign breast condition.

Ask your medical team which cancers you are at a higher risk of developing. Make sure you know the symptoms of these cancers – cancer is usually more treatable when it is diagnosed early. Cancer Research UK has information about different types of cancers.



Did you know?

Advances in treatment have led to more targeted radiotherapy, irradiating less of the normal tissue and using lower radiotherapy doses

> I read some time ago about investigations into the use of proton therapy for Hodgkin and non-Hodgkin lymphoma. Are there any trials around lymphoma and proton therapy? Do you foresee it becoming part of the treatment for lymphoma?

Radiotherapy was the first treatment used to cure Hodgkin lymphoma and is still an important part of treatment for many lymphomas today.

Radiation damages cells and as tumour cells are faulty and cannot repair the damage, they do not recover. Normal tissues can repair the damage and recover, although there may be long term consequences or 'late effects' depending on the area treated, including a low risk of a second cancer or tissue scarring.

Radiotherapy targets the area involved by lymphoma (known as 'involved site radiotherapy') and avoids normal tissue where possible. This increases the chance of cure and reduces the risk of late effects.

Conventional radiotherapy uses X-ray beams or photons to treat tumours. Radiotherapy can also be given with protons - beams of high energy particles which have very different physical properties.

Protons and photons travel through the body in different ways, and while they both deliver radiation to tumours, the characteristics of protons can lead to less radiation being deposited in normal tissues.

This may reduce the likelihood of late effects. This is particularly important when treating children or young adults, and when treating tumours close to critical structures such as the brain or spine.

Treatment with protons is available on the NHS for certain tumours, for example brain tumours in children. If a patient's consultant feels that proton beam therapy might be a suitable treatment they apply to a clinical panel who decides whether the proton beam therapy is appropriate. If this is the case, the patient is currently referred to a proton centre abroad, with costs covered by the NHS. NHS England have funded two proton centres in the UK, which are currently being built. The proton centre at the Christie Hospital in Manchester will open in 2018 and the proton centre at University College London Hospital in 2020.

Lymphoma is not currently on the NHS list of funded indications for proton therapy. However photon radiotherapy is delivered very safely and advanced techniques can already reduce the amount of radiation to breast tissue, heart and lungs. That being said, there may not always be clear benefits for choosing protons over photons for all lymphomas, depending on the area of the body and the dose given.

Ideally the use of protons or photons would be studied in a randomised controlled trial, but this would require a large number of patients and long term follow-up. A small study of the use of proton radiotherapy in mediastinal (chest) lymphoma (Hoppe et al) has shown that it seems to be as effective for treating lymphoma as photon radiotherapy, but it might take many years to determine whether there are other benefits, for example whether proton therapy has fewer late effects than photon therapy.

Research studies into proton therapy for lymphoma are being developed by the UK Lymphoma Radiotherapy Group. In the future, any trials for proton therapy in lymphoma will be listed on the clinical trials link www.lymphomas.org.uk/LMTrialsLink

New year new you

Do something amazing to help other people affected by lymphoma in 2018

The start of a new year is often a time for new beginnings and new resolutions. There's no better time to get involved to help make sure that anyone affected by lymphoma can get the help and support they need.

The Lymphoma Association relies totally on voluntary support from fantastic people – the little things that you do make a big difference for others:

1 Ask your local hospital or cancer information centre if they stock our information about lymphoma. If they don't stock our information, we can send them a starter pack.

2 Set up a direct debit quickly and easily online at www.lymphomas.org.uk/donate. Just £3 a month could help us put someone in touch with a buddy, providing help and reassurance from someone who has truly been there.

3 Sign up as a Lymphoma Association Ambassador to help raise awareness of lymphoma in your local area. We are currently looking for volunteers in London, South East and North West regions of England. For details go to www.lymphomas.org.uk/ambassadors.

4 Speak to your solicitor about making a legacy pledge to the Lymphoma Association. Leaving a gift in your will is a simple way to make a huge impact. It costs nothing in your lifetime and every gift will help. Make sure your loved ones are taken care of first, but after you've done that, if you'd like to make a gift to the Lymphoma Association, go to www.lymphomas.org.uk/legacies.

5 Sign up for a challenge event. A team of 10 from the haematology department at Lancaster Royal Infirmary are taking part in a velocity zip slide on May 19. As Haematology clinical nurse specialists, Sarah Cooney and

Julie Bethell commented: 'We aren't all daredevils and adrenaline junkies. To be honest, most of us are nervous about our challenge! For more information about their challenge, go to www.justgiving.com/fundraising/lymphomazipwirechallenge.

Are you looking to get fit in 2018?

We would love to welcome you to Team Lymphoma, which has guaranteed places in many 10K runs across the country; Kings Lynn or London Vitality in May; Virgin Sports London and Leeds in July and Leicester and Scotland in September.

We will be here to help you all the way. Go to www.lymphomas.org.uk/fundraising-ideas to find out more.



Does your hospital stock our information?



Preparing for the zip slide



Our dedicated information and support services are only made available thanks to voluntary donations, sponsorship and gifts in wills. Please consider helping today by visiting www.lymphomas.org.uk/donate or by calling us on 01296 619419.

thank you



‘Having Hodgkin lymphoma has been a catalyst to a healthier lifestyle’

‘I’d felt unwell for a year. I was tired and had a persistent cough. While going through hospital checks, scans and tests, I was convinced it was just a virus and would eventually clear up.

The news, in January 2008, that I had Hodgkin lymphoma, stage 3B, was a shock. In just a few moments, I went from being a happy 46-year-old, to not knowing what the future held for me. I had no idea what to tell my wife, Maria.

Up until that point, I kept asking questions about my health. Now I stopped and just listened. I started to feel like

something stronger than me had taken hold.

I was put on a six-month course of ABVD chemotherapy, given fortnightly. I found this fairly easy to cope with and was fortunate to have very few side effects. But after a couple of months I began to feel unwell again and feared the treatment wasn’t working. I was very short of breath and

couldn’t climb the stairs at home without stopping every couple of steps for a rest. It was decided that the bleomycin in the treatment was probably the cause, so it was removed. I got my breath back and finished treatment in August 2008. I was told that I had responded well to treatment and felt that the worst could be behind me.

“No-one knows what is waiting for them in terms of health, but I feel that keeping fit will have good benefits all round.”

I had follow-up checks every three months, then six months, then annually. The advice at the sessions slowly changed from checks to make sure I was clear of the original problems, to longer-term health advice. This included staying fit and eating healthily. There was also mention of longer-term effects of chemotherapy on the heart. I knew from regular checks that I had slightly high blood pressure, and eventually I was put on blood pressure tablets. Although I felt fine, I wanted to take a longer-term view of my health.

My wife and I wanted to take more control, and although we had enjoyed hiking and gardening as exercise, we both felt there was more we could do. At the same time, I became a Lymphoma Association buddy, as I felt I was doing well and hoped I could encourage others going through treatment.

From reading, I knew that raising my heart rate was good, so a couple of years after finishing treatment, I decided to do some gentle running. I wasn't going far, maybe a mile or so, but to my surprise I enjoyed it - I'd hated it at school! Friends mentioned an organised event called

Park Run, which is a regular Saturday run of around three miles. My first Park Run time was 32 minutes and I was in 102nd place. Mo Farah wasn't going to be too worried, but I was pleased.

As the evenings lengthened and the weather got worse, I found running less appealing, but I didn't want to give up exercise. Maria and I decided to join the gym at our local leisure centre. I told them about my lymphoma and the treatment I had had, and the instructor put together a program. I started in a very gentle way, gradually building up.

I had been a regular gym user in my twenties (now 30+ years ago) and could remember what I could do back then. To my surprise, I found that with a bit of effort, I could still do many of the same exercises. I did have to be careful around some weak areas (I'd had a hernia operation), so was always careful not to overstress that.

We had a holiday in Utah and Nevada to look forward to, and exercise made us both feel and look better. Maria and I started to look more closely at our diet, and began to eat more healthily. We ate fewer

cakes and desserts and better main courses. We both noticed improvements and enjoyed what we were achieving together. We still socialised as much as we wanted to, but tended to limit some of the excesses when we were out with friends.

I feel as though my cancer days are long behind me, but I am still very mindful that all of the original advice is important and would seek help if I was worried about anything. But the healthy lifestyle has given me a more positive mindset and improved me physically.

No one knows what is waiting for them in terms of health, but I feel that keeping fit brings benefits all round. I feel great and perhaps most surprisingly, being ill has been a catalyst to a healthier lifestyle for me.'

John



Did you know?

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



Exercise & lymphoma

Research suggests that exercise can improve both physical and mental wellbeing.

A study carried out over three years looked at the benefits of exercise in 122 people with Hodgkin and non-Hodgkin lymphoma. It found that aerobic (cardiovascular or 'cardio') exercise improved physical functioning and quality of life, even for people who were undergoing chemotherapy.

A review of 28 exercise programmes found that exercise can help to reduce cancer-related fatigue. Another analysis of 44 different studies (with a total of over 3,000 participants who were living with various types of cancer) had similar findings.

How much exercise?

The recommended amount of exercise depends on several factors, like your general health and whether you are currently having treatment for lymphoma. For some people, a little exercise is enough. Others are motivated to set goals and challenge themselves.

In the UK, current recommendations on exercise for people with cancer who are otherwise well are the same as for people without cancer. For adults, this is at least 30 minutes of activity 5 days a week. Ideally, you should do

some physical activity every day. Visit GOV.UK website for more information about UK recommendations on physical activity. NHS Choices have examples of light exercises at www.nhs.uk/livewell/fitness.

Because lymphoma and its treatment has put a strain on your body, the time your body takes to recover after exercise can be longer than it was before. It is therefore recommended that you increase activity levels gradually, especially if you are not used to exercise. Build up the number of times a week you do physical activity slowly and add more 'everyday' physical activity, such as taking the stairs instead of the lift.

Exercise doesn't have to mean working out at a gym or running, and most people exercise as part of their daily life, for example when going for a walk, climbing the stairs, vacuuming, carrying shopping or gardening.

What are the different types of exercise?

Aerobic (cardiovascular) activity increases your heart rate while you are doing it and for a short while afterwards. Examples include running, swimming and high-intensity cycling. The benefits of aerobic exercise include weight control and reduced risk of coronary heart disease.

Muscle-strengthening exercises, such as lifting weights, help to regulate blood pressure and blood sugar level. They also keep your bones healthy, improve strength, posture and balance and help to maintain a healthy weight. Daily activities such as digging, carrying shopping and vacuum-cleaning also strengthen muscles. It is important to maintain strength in your muscles. Any decrease in activity can lead to muscle weakness and fatigue (a common side effect of many treatments for lymphoma, including chemotherapy). This can result in a cycle where you do less activity, feel more tired, do less activity and so on.

Flexibility exercise can help keep you mobile and active by making the muscles more supple. Activities that incorporate flexibility

exercises include yoga and Pilates. It is important to seek advice from your medical team about the type and intensity of exercise that is suitable for you.

When should I avoid exercise?

During or soon after your treatment for lymphoma, your medical team may advise against particular activities if you have certain side effects, such as thrombocytopenia (low platelet count), neutropenia (low neutrophil count), anaemia (low red blood cell count), peripheral neuropathy (damage to the nerves of your peripheral nervous system), diarrhoea or vomiting. Swimming, for example, in a public pool carries risks if you have any of these conditions or if you have a central line in place.

Does exercise aid recovery?

Many people wonder if it is better to rest and save energy than it is to exercise. Although rest is essential in helping you recover, evidence shows that it is both safe and beneficial to exercise during and after treatment for lymphoma. It is important to realise,

however, that you might be able to do less exercise than you did before you had lymphoma.

Exactly how exercise helps recovery is not yet known; however, its potential to shorten recovery time, ease fatigue and boost mental wellbeing are well recognised.

Some people see the end of treatment as a good time to begin a healthier lifestyle. Many local gyms offer programmes for people recovering after cancer treatment. You might prefer other forms of physical activity such as gardening, dance classes, Pilates or Nordic walking.

Chosen an activity you enjoy as then you are more likely to keep doing it. Also find a partner or other people to do it with, as this provides a good opportunity to socialise. You are also more likely to keep doing it if you don't want to let someone down.

With thanks to Mairéad Mulhall, Macmillan Lymphoma Clinical Nurse Specialist, for reviewing this piece. This is an extract of our exercise and lymphoma information which can be viewed at www.lymphomas.org.uk/exercise

Lymphoma Association Support Groups near you

- Aylesbury
- Bangor
- Bath
- Bolton
- Cambridge
- Canterbury
- Cardiff
- Cheltenham
- Colchester
- Colne
- Coventry
- Driffild
- 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
- Wirral
- Lymphoma Association Support (closed Facebook support groups): North West, South West, Yorkshire & North East



Bernard Rice

Diagnosed 50 years ago

Leicester support group leader, Bernard Rice, was initially diagnosed with lymphoma in 1968, when he was 20 years old. As Bernard says: 'It's true that I am, remarkably celebrating 50 years since diagnosis. I did have a celebration after 40 years at the hospital I was treated in. I keep saying I'd like to do something to celebrate 50 years, but haven't come up with anything as yet. I don't intent to jump out of an aeroplane, do wing-walking, bungee-jumping or anything so extreme, but I'll try and conjure up something!'

Watch Bernard on bit.ly/BernardsLymphomaStory

New support group opening in Bolton

We are delighted to announce our latest support group. The Bolton group will meet on the first Tuesday of alternate months from 5.30-7pm at the Macmillan Information Centre, Royal Bolton Hospital, Minerva Road, Bolton BL4 0JR. The first meeting will be on Tuesday March 6.



If you'd like to know more about lymphoma 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
- Facebook: @LymphomaAssoc
- Twitter: @LymphomaAssoc
- Instagram: @lymphoma_association

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

Our support groups are great places to meet, catch up and share information with others affected by lymphoma.

Keeping discussions interesting and engaging is important, and we are delighted to hear about all the interesting talks that take place around the country.

Topics of general interest to people living with lymphoma prove really helpful, like 'fatigue' or 'coping with the symptoms of lymphoma'.

'Travel insurance' always sparks a healthy debate!

Many groups invite members of their medical team to go along and talk to them. Consultants and clinical nurse specialists offer insights and updates on lymphoma. They may also be able to suggest other members of the team who could go along, such as a

clinical pharmacist, dietician, radiographer or physiotherapist.

Macmillan, Maggie's, Healthwatch, Citizens Advice and Independent Cancer Centres are usually happy to go along to meetings to talk about their services and often have contacts with complementary therapists or benefits advisors.

If you run a support group and would like tips on arranging talks, go to www.lymphomas.org.uk/supportgroups or call 01296 619400.

We'd love to hear about talks you hold. Together we can make sure our meetings continue to be interesting and supportive.

Interesting talks in your area

10 years supporting Milton Keynes

In January, Milton Keynes support group celebrated their 10th anniversary by holding a tea party.

Lymphoma Association Chief Executive Jonathan Pearce and Regional Development Manager Jilly Vickers went along. As Jonathan said: 'Each of our support groups is unique. At Milton Keynes it was heartening to realise how valued this service is in connecting people locally.'





Live your life programme expands

One year on from receiving Big Lottery Funding to roll out our Live your Life programme, we have held over 30 events around the country, reaching over 450 people affected by lymphoma.

Our *Live your Life* workshops are one-day events for people who have finished treatment or are on 'watch and wait'. They cover what lymphoma is, how to cope with it, dealing with the emotional aspects

of lymphoma and practical aspects like diet and exercise. They are facilitated by someone with personal experience of lymphoma, in partnership with the local Clinical Nurse Specialist. The workshops are held in a relaxed, informal setting where people get the chance to meet others affected by lymphoma and share their experiences.

Find out more about the workshops and to keep up-to-date with the latest *Live your Life* updates and locations at www.lymphomas.org.uk/live-your-life.



'Thank you so much. I found the day inspirational and felt privileged to be present. Well run, comfortable, and excellent content.' *Theresa Peters, Haematology CNS (pictured left with Sharon Burge).*

In the Spring we are launching our young people's *Live your Life* workshops for people aged 18-30 who have lymphoma. These workshops will cover similar topics, but also include working and studying after a lymphoma diagnosis.

Over the course of 2018 we will be developing our *Live your Life* resources further to include video and online support materials.

↩
Last year, after attending a *Live your Life* event participants told us:

'I feel better able to cope with the emotional aspects of a lymphoma diagnosis'

'I am more aware of which signs and symptoms to report to my medical team.'

'I feel more comfortable contacting health professionals if I have any concerns about my health.'

Radisson Blu Hotel, Manchester Airport, Saturday 12 May

- Learn more about lymphoma from consultants and specialist nurses.
- Talk with others who have been through a similar experience.
- Lunch and refreshments are included in the cost of the conference ticket.

Find out more at [www.lymphomas.org.uk/
NationalConference](http://www.lymphomas.org.uk/NationalConference)

‘The knowledge from the presenters and medical team was amazing’.

‘Everyone was friendly and ready with lots of information, and the speakers were encouraging’.



National Patient conference

Lymphoma Management course: Keble College, Oxford University, Mon 25-Tues 26 June.

We work closely with health professionals to help ensure people affected by lymphoma get the best treatment and care. This includes a specialist education and training programme for those with an interest in lymphoma.

In June, our Lymphoma Management course will provide a comprehensive overview of the diagnosis, treatment and management of lymphomas, delivered by lymphoma specialists

across the UK. If you are a health professional and would like to find out more, go to [www.lymphomas.org.uk/
LymphomaManagement](http://www.lymphomas.org.uk/LymphomaManagement)



Specialist course for clinicians

Meet others, feel heard, share experiences

Lymphoma Association support groups

'Just being in a group where everyone has had a similar experience means that you can openly discuss any problems you might have.'

'I quickly realised how valuable face-to-face support was. I have made some wonderful friends in the group and not only find it extremely sociable, but through the organised talks from medical experts, I have also learned a lot about the disease.'

Find your nearest support group at www.lymphomas.org.uk/supportgroups



Lymphoma Association
3 Cromwell Court, New Street,
Aylesbury, Bucks HP20 2PB
www.lymphomas.org.uk
Freephone helpline 0808 808 5555

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

Our dedicated information and support
services are only made available thanks
to voluntary donations, sponsorship
and gifts in wills. Please consider
helping today by visiting
www.lymphomas.org.uk/donate or
by calling us on 01296 619419.

The Lymphoma Association is a registered charity in England and Wales (1069395) and in Scotland (SC045850). A company limited by guarantee registered in England and Wales (03518755).



Lymphoma
association

