Understanding imaging

Talking about cancer-related fatigue

Meet our Beacons of Hope

CLINICAL TRIALS UPDATE

LATEST NEWS
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.

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Cover: Read about Morag (pictured with her husband Richard) on page 18
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Photo: Kelly Jo Hearsey

Read the latest news and views on our Lymphoma Matters blog
www.lymphomas.org.uk/LMBlog
Moving into the field of research

There are a number of exciting new developments to look out for in 2017. First, following the award of Big Lottery funding, we will see the full roll-out of our Live your Life education and survivorship programme, which we aim to make available across the UK via clinical nurse specialists and support groups, and also as an online resource.

Our recently launched Lymphoma TrialsLink will continue to grow and develop as we aim to cover all the lymphoma trials open in the UK, including phase I trials. For healthcare professionals, we’re expanding the range of education and training events and resources we offer, including launching our online National Lymphoma Training Programme later in the year.

There are many other developments that I could flag up, but perhaps the most significant initiative is our decision – taken at the end of last year – to move into the field of research. It’s early days, but what we plan to do is develop and fund a research programme targeted at lymphoma-related areas not adequately provided for at the moment. We want to involve people affected by lymphoma, their doctors and their nurses, in deciding on the programme’s priorities. But it’s likely they will include quality of life issues, specific areas where there are unmet needs or poor outcomes, and support for innovation or the acceleration of new research.

Whatever we settle on we will continue to specialise in lymphoma and make a big impact on the lives of people living with lymphoma.
Lymphoma Association attends Parliamentary Roundtable event

A series of recommendations aimed at improving outcomes for Hodgkin lymphoma (HL) patients were agreed at a Parliamentary Roundtable event in November. The event, sponsored by Nic Dakin MP, brought together MPs, policy experts and patient groups. The Lymphoma Association were key speakers, together with trustee Dr Graham Collins and a patient advocate.

The discussion was on the clinical challenges in treating HL and the current unmet needs that must be addressed to improve outcomes and experience for HL patients. Recommendations put forward included:

- Improved psychological support.
- The recovery package, as outlined in the Cancer Strategy, should be cancer-type specific.
- Primary care clinicians should be supported by diagnostic tools to identify signs and symptoms of blood cancer.
- NICE should clarify the system it plans to use to assess data for medicines that treat small patient populations, such as blood and rarer cancers.
- The Health Select Committee should undertake an inquiry into the prioritisation process NHS England uses to determine which conditions are suitable for specialised commissioning.
- Improved coordination between national and local commissioning to streamline care of people undergoing treatment for blood cancer.

Erika Murigi, our PR and public affairs manager, said: 'This event provided a valuable opportunity to discuss issues faced by people affected by HL with an important group of influencers.'

Ibrutinib now available on the NHS for CLL

On 25 January 2017, NICE published guidance recommending the use of ibrutinib in England for people with chronic lymphocytic leukaemia (CLL) who have had at least one previous treatment, or who have CLL with certain genetic changes (17p deletion or TP53) that mean standard chemo-immunotherapy is not suitable. ibrutinib was previously available for these uses through the Cancer Drugs Fund, but now goes into routine use on the NHS. NICE decisions on the use of ibrutinib for some people with mantle cell lymphoma or Waldenstrom’s macroglobulinaemia are expected shortly.
EMA recommends two new drugs for lymphoma treatment

The European Medicines Agency has recommended two new drugs for approval for treating lymphoma. These recommendations now go to the European Commission, which will make the final decision on whether the drugs can be marketed in Europe.

Until now, MabThera® was the only approved version of rituximab for treating lymphoma. Truxima® is the first biosimilar to rituximab expected to be approved for use in Europe. If approved, Truxima® will be available for the same uses as MabThera®. Clinical trials have shown that Truxima® is as safe and effective as MabThera®. Importantly, the availability of biosimilars can reduce the costs of drugs.

Ledaga® (chlormethine or nitrogen mustard) is a gel formulation of a chemotherapy drug, which can be applied directly to the affected skin in people with mycosis fungoides-type cutaneous T-cell lymphoma. Skin lymphomas, like mycosis fungoides usually require treatment from time-to-time and Ledaga® could provide a new treatment option.

Psychology service

Maggie Rayfield has joined the Lymphoma Association as a clinical psychologist. Based at Stoke Mandeville Hospital in Aylesbury, Maggie provides psychological support to individuals and also groups of people affected by lymphoma.

This psychological support service is a pilot, which we hope to roll out across the country within NHS Trusts. To find out more, go to www.lymphomas.org.uk/Psychology

Negative NICE recommendation for brentuximab vedotin

The National Institute of Health and Social Care Excellence (NICE) is proposing not to recommend brentuximab vedotin (Adcetris®) for routine use on the NHS in England for treating people with relapsed or refractory CD30+ Hodgkin lymphoma (HL).

The drug, which has been available for some time through the former Cancer Drugs Fund, is currently going through its NICE Technology Appraisal. In an appraisal consultation response, the Lymphoma Association wrote: ‘Since brentuximab has become available for this group of Hodgkin lymphoma patients, it has rapidly become the standard of care. As such we call on NICE and the company to review the evidence and pricing so that people can have access to a potentially life-saving treatment that also has significantly fewer side effects and after effects than traditional chemotherapy.’

The third appraisal committee meeting will take place in mid-February, with NICE expected to make its final decision sometime in March.

Major lymphoma research report to be published

The Lymphoma Association commissioned Quality Health, who is responsible for the National Cancer Patient Experience Survey, to gain up-to-date data on the information and support needs of people with lymphoma. The results of the survey of more than 3,000 lymphoma patients are due to be published soon.
Diagnosed with follicular lymphoma in February 2006, Caroline had no idea what was ahead.
I was referred to haematology, and as a physiotherapist I started to suspect lymphoma, even though the symptoms weren’t typical. I had an ultrasound scan and a needle biopsy through my spine using a CT scan to ensure the sample was being taken from the right place. I needed a bone marrow biopsy and, as the needle biopsy had been painful, I asked for sedation.

In February 2006 I was diagnosed with follicular lymphoma, a type of B-cell low-grade non-Hodgkin lymphoma. I was told I had large tumours around my aorta, above and below my diaphragm, and the lymphoma had also spread to my bone marrow, meaning I was stage 4.

I’d just turned 40 and had 2 young sons. Max was 8 and Harvey was 5 at the time. Sadly there has been a lot of cancer in our family, so despite how young they were, I knew my children would have some understanding. I didn’t want them to overhear hushed conversations, but wanted to be open with them and let them ask me any questions they wanted. Generally they coped very well and just got on with life.

‘I chose to be treated at the hospital where I work.’

My treatment was R-CHOP chemotherapy and I chose to be treated at Lewisham Hospital where I work as a physiotherapist. I really wanted to continue working and thought I could fit appointments around breaks. The first time they gave me rituximab (an antibody – the ‘R’ in R-CHOP) they started with a small dose to check I didn’t have an adverse reaction. Then the dose was progressively increased, doubled over several hours. The 3rd dose sent me into anaphylactic shock. I felt my throat closing up and the room was spinning, so I pressed the emergency buzzer. The symptoms were swiftly reversed with an injection, but it was frightening.

I had prepared for the chemotherapy by having my hair cut really short, which I thought looked alright. I thought that if I’m going to lose my hair I might as well try out different colours and styles, so bought a number of wigs. But I really didn’t like them; they felt itchy and hot and looked wrong. As it turned out, my hair didn’t fall out, but my hair, eyebrows and eyelashes became thinner.
I contacted the Lymphoma Association and found them enormously helpful and calming. I was able to talk about things that I didn’t want to talk to my doctor about.

I was put in contact with a buddy, which was both helpful and reassuring. I am now a buddy for the charity myself, which is important to me, as I want to be able to give others hope and support, just as my buddy did.

On 16 August 2006, a PET scan revealed that I was in complete remission. However, my doctor suggested carrying out a ‘rainy day harvest’ in case I needed to have an autologous stem cell transplant (using my own stem cells) in the future.

I struggled with fatigue for about a year after treatment and at times it could be overwhelming. I found myself trying various things to assist my recovery such as relaxation and meditation, green tea and cutting out caffeine, various vitamin supplements and eating organic. I don’t know whether these things helped, but it made me feel like I was doing something active. I also joined a local choir, which I found very therapeutic, especially as I’ve been interested in singing and music for many years. I noticed my attitude to things changed. In the

Follicular lymphoma is a B-cell lymphoma and is the most common type of low-grade lymphoma. It tends to grow slowly, and by the time people experience symptoms, it is often at an advanced stage (stage 3 or 4).

People do not always need treatment straightaway. Instead, doctors may recommend the ‘watch and wait’ approach. When follicular lymphoma needs treatment, most people will have a combination of chemotherapy and antibody therapy, such as R-CHOP or R-CVP. The ‘R’ is the antibody rituximab which attaches to a protein on the B cell surface called CD20. Once people are in remission, they will probably be offered maintenance treatment for up to 2 years using the antibody treatment. This should keep the lymphoma in remission for longer. As follicular lymphoma is more common in older people, gentler treatment with oral chlorambucil, often given with prednisolone (a steroid), may be suggested.
‘Last year I turned 50 and I feel that in many ways surviving cancer has been life enhancing. I have now been lymphoma-free for 10 years and have done things I could barely have dreamed of doing before I was diagnosed.’

past I may have passed a restaurant and thought it might be nice to go there sometime – now I book it. I dress up far more, and don’t keep clothes, china or glass for ‘best’. We’ve also done far more travelling than ever before, and I grab every opportunity to have ‘bucket list’ moments. All of this has been life-enhancing. My last chemotherapy was 10 years ago and check-ups are now annual. But I never quite feel that I can relax 100% health-wise. I suppose if you have breast cancer, you know where to check for lumps, but with lymphoma I am aware it can appear almost anywhere, which makes any strange unexplained pain or symptom potentially worrying.

I wonder if there comes a time when you don’t worry about aches or pains? I suspect not.

In 2012 Lewisham and Greenwich NHS Trust was approached by the BBC as 1 of 4 workplaces forming choirs to compete in the TV series The Choir: Sing While You Work with Gareth Malone. I have a real interest in music and was in a punk band years ago on lead vocals, bass guitar and violin. So when staff were invited to audition, I was really keen to get involved. The audition was intense in front of Gareth Malone, the full camera crew and others waiting for their audition. I was thrilled to be 1 of the 30 staff chosen.

It was a really exciting time, and in 2013, a year after the programme went out, Lewisham and Greenwich NHS Trust produced a single - a mash-up of Fix You by Coldplay and Bridge Over Troubled Waters by Simon and Garfunkel, which was used as the soundtrack to a video of us caring for patients. A junior doctor had the idea of getting the NHS to Xmas number 1, to highlight all the positive things that happen in the NHS every day. She started promoting our single on social media and got a big campaign going. Chris Evans invited us onto his Radio 2 programme just before Christmas and we sang the single live, and then, to our amazement, Justin Bieber – who was heading for the number 1 spot – asked his 85 million Twitter fans to buy our charity single!

Chart success
We achieved the 2015 Christmas number 1 UK single. This was followed by a record deal and an album entitled Something Inside So Strong. This was released just before Glastonbury, and to our astonishment, we were invited to perform there; an absolute once-in-a-lifetime, top of my bucket list experience. We were also invited to sing at the opening of the FA Cup Final in 2016.

Last year I turned 50 and I feel that in many ways surviving cancer has been life enhancing. I have now been lymphoma-free for 10 years and have done things I could barely have dreamed of doing before I was diagnosed.

If you would like to be put in contact with a buddy, someone who has personal experience of lymphoma, contact us on 0808 808 5555 or email information@lymphomas.org.uk.
Here we look at the most common types of imaging used for people affected with lymphoma - what they are, how they work and why you may have one type of test over another. Some possible future developments are also mentioned and Dr Sharma also explains why you will not routinely be offered imaging tests at follow-up.

Before planning any imaging, your doctor will consider what needs to be established by the test, so that the most appropriate imaging can be planned. A scan will only be performed if there is a question to answer, or the scan is going to change the management of the disease.

Imaging is a powerful clinical tool, and is used for investigating potential health problems, aiding diagnosis and disease management. In this article, Dr Bhuey Sharma, Consultant Radiologist at the Royal Marsden Hospital, London, describes the various types of scans that are available and explains when and why scans may be used.

Understanding imaging
‘Before planning any imaging, your doctor will consider what needs to be established by the test, so that the most appropriate imaging can be planned.’

**X-ray**

Between the 1960s and 1980s, X-rays were part of the standard management for people with lymphoma. It is a simple imaging test using radiation exposure (which is very low). It is like having a photograph taken, but it uses X-radiation rather than visible light. Like a standard photograph, it only takes a couple of seconds to take the image. X-ray imaging provides basic, but very useful information. Today, it is used in connection with the diagnosis of infection, such as a chest infection. If, for example, you go to your GP with chest pain or shortness of breath, then you may be referred for a chest X-ray. This is a simple and effective test to determine whether there is something wrong. If that is the case, you will be referred for other imaging tests.

**CT scan**

Computed tomography or the CT scan was invented in the early 1970s and has revolutionised cancer care. Most people with lymphoma will have a CT scan at the beginning and throughout the management of their disease. It is a standard, extremely useful test for most cancer types. A CT scan involves a large number of X-ray images taken with the X-ray tube rotating around the region of the body that is being scanned. The images are processed by computer to generate a series of slices through the body, each showing the anatomy in the slice. The detail provided by a CT scan allows abnormalities to be examined, and can enable an assessment of the type of disease.

A CT scan involves a radiation dose to the patient. Scans should therefore only be performed if medically justifiable, eg the benefit to the patient of the scan outweighs the risk of the radiation exposure (although the ‘radiation dose risk’ to the patient of a single CT scan is very low). A CT scan is performed with the person lying on a specially designed table, which enters the scanner. A typical CT scan lasts about 10-20 minutes, although it depends on how much of the body is being scanned.

**MRI**

The images produced by MRI or magnetic resonance imaging are similar to those from a CT scan, in that they show slices throughout the body with anatomical detail. However, MRI does not give the patient a radiation dose, but instead a combination of radio waves and strong magnetic fields generate the images.

**The MRI scan cannot replace CT because it does not give good information on various parts of the body, like the lungs, which are important areas to assess with lymphoma.**

However, there are parts of the body where MRI provides a better image resolution and contrast, specifically the brain and looking at the spinal cord.

An MRI takes longer to perform than a CT scan, and around 25% of people find it claustrophobic. Some people also cannot have an MRI scan – eg people with pacemakers, and certain types of post-surgical bone/
joint metalwork which are not safe in the strong magnetic field. The table slides into a narrow tunnel and the scan, which is very noisy, takes from about 30 minutes. People are encouraged to take their own music with them if they wish, which they can listen to through headphones during the scan. You can ask for a sedative if you are anxious about having this type of scan.

**PET**

Although you may hear it called just a PET scan it will actually be a PET/CT (see below). PET – positron emission tomography – was invented in the 1970s and was initially used for neurodegenerative and cardiac conditions. However, since the 1990s it has gradually come into use in cancer care, and there is ongoing research into the use of PET for people with lymphoma. The process of acquiring a PET scan takes some time.

A glucose-like compound containing a radioactive isotope is injected into the person’s blood stream. The patient lies on the table of the PET machine, which then detects where the radioactive signal comes from, and so localises the site of abnormality. The scan can take around 40 minutes, although with newer machines this can be reduced to around 10 minutes.

A PET scan gives additional information which can be helpful in staging and response assessment. For example, a CT scan can show that something of a few centimetres in size is still there, but the PET scan will tell if this is disease activity as opposed to scar tissue.

**Combined PET/CT**

PET is not used alone any more. With PET you get an image that shows glucose uptake to indicate activity. A PET produces a black and white image, with the dark regions showing where the glucose has been taken up. However, it does not show the anatomical detail, so doctors had to guess where the black dots were – were they in the kidney or bowel, which may be normal, or is it showing disease activity?

Townsend and Nutt were physicists who had the idea of joining PET and CT, which has been available since 1999. The CT gives the anatomical picture of the body in fine detail whereas the PET shows where there is any activity.

PET/CT is becoming more available; large mobile vans also go around with these scanners to a large number of NHS hospitals.

**PET/MRI**

PET/MRI is very new – there are only a couple of PET/MRI scanners in the UK and these are currently of research interest, compared with the many CT and MRI scanners available. Investigations into the use of PET/MRI are taking place and one area where it may be important is in multiple myeloma. However, it will still be some time before research data from PET/MRI scanners has been analysed and before this type of scan may be available. PET/MRI is not generally used for patient clinical care at present.
What is involved in reporting on scans?
Reports on scans are produced by highly trained doctors who are looking at complex datasets with thousands of highly detailed image slices – images that are the result of processing many individual images. Lymphoma is a complicated disease with over 60 subtypes with different natural biology. The radiologist (person reporting the scan) needs to understand the tumour biology in order to know where to look for disease and the way it could develop.

A detailed report will be available for the multi-disciplinary team (MDT) to aid with diagnosis or disease management.

How long does it take to report on a scan?
Practice varies from hospital to hospital. A report could be written within an hour of a scan being performed. However, during the course of a day in a large hospital hundreds of scans may be carried out. People get worried about the delay between the scan and the report, but for urgent scans, for example if the doctor is worried about a blood clot or there is concern about cord compression, a very rapid assessment will be performed and the radiologist will quickly contact the doctor looking after the patient directly.

To what extent do scans aid diagnosis and staging?
With lymphoma, tissue is all important and you cannot make a diagnosis without a biopsy.

In certain cases, imaging can be helpful in telling the doctor where to take the biopsy from. The imaging (scan) data and the pathology (biopsy) data taken together will then define the stage (extent) of the patients disease.

Are GPs reluctant to refer people for scanning?
It is incredibly difficult for any GP to recognise who needs to be referred to hospital for further tests. For example, if 1,000 people report symptoms, it is difficult for the doctor to identify the very small number who may have something more serious, like a cancer.

Why aren’t scans regularly used at follow-up?
The NICE 2016 Guidelines direct that imaging tests should only be carried out if they will change patient management or outcome.

For some forms of cancer, such as bowel cancer, scans are regularly used in follow-up. For lymphoma, relapse is very rarely picked up at follow-up because lymphoma tends to declare itself clinically. People will have a strong suspicion that their lymphoma has relapsed because they will get symptoms, such as swollen lymph glands, unexplained significant weight loss, new drenching night sweats etc and at this stage their medical team will organise tests to investigate this. This is backed up by numerous research studies which show that follow-up scans for lymphoma do not change either patient management or outcomes, because relapse is rarely picked up in this way.

Research trials and scans
A number of research trials are being performed in lymphoma. People will often have imaging scans as part of the research trial. CT scans are often included, with PET scans in numerous trials, and sometimes other scans like MRI. Sometimes people will have slightly more scans in a research trial than would normally be the case under routine patient assessment. However both the type and number of scans in every research trial conducted in the UK will have been carefully thought about and checked by regulatory authorities. Scans are only performed if they are considered helpful for the patient and to safely assess the effectiveness of the treatment being assessed.

Useful reading
NICE NHL 2016 Information for Patients pathway can be accessed at www.nice.org.uk/guidance/ng52
Join Team Lymphoma for 2017

If you are up for a new experience in 2017, then please join Team Lymphoma and take part in a challenge event to raise awareness and money to help people affected by lymphoma.

We currently have places available in the following events:

**Walking/Adrenaline events:**
- Isle of Wight Challenge (April)
- London 2 Brighton Challenge (May)
- Cotswold Way Challenge (July)
- South Coast Challenge (August)
- Thames Path Challenge (September)
- Tough Mudder Challenges (nationwide)

**Running events:**
- Paris Marathon (April)
- Nottingham 10K (May)
- Vitality London 10K (May)
- Great Women’s Run, Glasgow (June)
- Burnley 10K (June)
- British 10K, London (July)
- Leeds 10K (July)
- Great North Run, Newcastle (September)
- Great Bristol Half Marathon (September)
- Berlin Marathon (September)
- Sheffield 10K (September)
- Royal Parks Half Marathon, London (October)
- Yorkshire Marathon (October)

**Cycling events:**
- Nightrider London (June)
- Edinburgh Night Ride (June)
- Ride London (July)
- London to Brighton (September)

Once you are signed up, we will provide:

- Unlimited support and encouragement throughout your training and in the run-up to the event.

- Fitness guidelines to help keep you on track.

- Advice to help you maximise your fundraising, with information to help inspire your sponsors and raise awareness through your local newspaper.

‘When everybody else is at a loss to know what to say to you, the people at the Lymphoma Association know exactly what to say. You can’t put a price on that, but it costs money to keep the service there.’ Sheila
You can get your family and friends to sign up as Lymphoma Lights if they are planning to go along on the day to cheer you on. They can help raise awareness along the route. All they need is a loud cheering voice and strong arms to wave small flags and banners.
The Beacons of Hope Awards were held at the Houses of Parliament and celebrated the end of our 30th anniversary year.

Selected by a group of external judges, including our patron, Lord Menzies Campbell, clinical nurse specialist Micaela Plucinski and Director of the Roger Counter Foundation, Richard Bagley, the awards recognise people who make a difference to others living with lymphoma. BBC Radio 4’s Susan Rae presented the awards to these inspirational people.
1 Helen Marie Webb
After being diagnosed with Hodgkin lymphoma in 2013, Helen Marie has raised more than £6,000 for various charities.

2 Ellie Philpotts
Ellie, who was diagnosed with Hodgkin lymphoma while still at school, helped us develop a range of materials aimed at teenagers and young adults.

3 Phil McGrenaghan
Phil was nominated for improving provision of information and support services in Northern Ireland after his wife’s lymphoma diagnosis. Together they founded Cancer Connect Northern Ireland.

4 Linzi Retallick-Schmid
(see 23)

5 Lara Rowley
Lara is an advanced nurse practitioner for bone marrow transplants. Her nominator described Lara as: ‘Everything a medical professional should be. Without Lara, the allograft process would have been much tougher.’

6 Caroline (Caz) Edwards
(see 23)

7 Janet Jeffries
After receiving treatment in her local haematology day unit, Janet wanted future patients to be treated in comfort, so started fundraising for the unit. Her nominator added: ‘The money she is raising is fantastic, but the bonds and support with fellow patients is why I nominated her.’

8 Julie Parr
A Macmillan Nurse Lead for St Helens and Knowsley Teaching Hospitals, Julie was described as: ‘A totally unique and extraordinary person who has been a rock and endless support for my family and me’.

9 Helena Sheriden
A lymphoma clinical nurse specialist, Helena was described as: ‘Calm, caring, efficient and compassionate and is a shining example of the very best of clinical nurse specialists working in a multi-disciplinary team.’
10 Rosemary Gossington
Rosemary is a longstanding Buddy and a mentor to other Buddies. She helps raise awareness of lymphoma, and won her award for the many years of supporting people.

11 Freya Rodger
In 2015, Freya committed to ‘trying her hand’ at every Olympic sport open to women as part of a ‘Freyathlon’ fundraising challenge. Her nominator said: ‘Through Freyathlon, she has bought people together, and by sharing her experiences shown people that anything is possible.’

12 Dr Simon Knowles
Dr Knowles is a GP in Cornwall. He was nominated by a patient who wrote: ‘Without Dr Knowles’ quick referral, the treatment team at the hospital wouldn’t have been able to do their jobs.’

13 Mark Reay
Since going into remission, Mark has cycled more than 3,000 miles raising awareness of blood cancers and money for charities. His nominator said: ‘Mark is an inspiration to others with the same condition.’

14 Helen Zehnder (see 20)
15 Sarah Whittaker (see 20)
16 Anna Trubridge
Anna, an assistant lymphoma nurse at Queen Alexandra Hospital, was nominated for truly making a difference to the lives of her patients. Her nominator wrote: ‘Anna’s support helped my husband and family through a very stressful time.’

17 Morag Day
Morag co-founded the Poole Lymphoma Association support group in 2003 and has been running the group ever since. A nurse, a mother and marathon runner, Morag has undergone three bone marrow transplants and is undergoing further treatment. (Morag is pictured with her husband Richard on the front cover).

18 Paul Smith
Paul retired as the Leader of the Haematology Trials Group at Cancer Research UK & UCL Cancer Trials Centre in July 2016. He oversaw more than 50 clinical trials for lymphoma. He was nominated by his colleagues because: ‘Whether they are currently on a trial or not, most lymphoma patients in the UK receive treatment that is in some way shaped by the work he did.’

19 Susie Gander
Diagnosed with Hodgkin lymphoma in 2014, Susie was nominated after raising awareness of lymphoma and more than £2,000 in fundraising. Her nominator described her as: ‘An inspiration who brings light to all around her.’

20 Dorothea Read (and team)
Dorothea Read is the lead hypnotherapist of a
small team of voluntary hypnotherapists. They offer their services free to patients undergoing chemotherapy, helping them to overcome severe anxiety issues and needle phobias.

21 Carolyn Spiller (see 20)

22 Helen Cosh

Helen, a haematology day unit sister, was nominated for implementing various innovations in the unit to benefit patients undergoing chemotherapy. Her actions have made a real difference to the lives of patients.

23 Dr Adam Forbes

Dr Forbes and clinical nurse specialists Caz and Linzi were nominated for offering amazing reassurance, support, help and guidance. They were described as: ‘Three special people who deserve recognition for the amazing job they do every day for all of their patients.’

24 Harry Gipson

A keen rugby player, 13-year-old Harry organised a charity rugby match in aid of a teammate’s family who were dealing with lymphoma. Raising more than £1,600, his award was the family’s way of thanking him for thinking of them.

Also winning a Beacons of Hope Award, but not pictured:

25 Carol Jarvis

Carol has had a long battle with Hodgkin lymphoma. She has helped campaign for access to a life-saving treatment, supported other lymphoma patients and helped raise awareness of the issues faced by people with lymphoma.

26 Ann Miskimin

Ann has been helping lymphoma patients for around 20 years and is an original member of the Manchester Support Group. One of her nominators wrote: ‘Ann makes a difference to lymphoma patients through her dedication, professionalism, and generosity of time.’

Dr David Watson

Consultant Haematologist Dr Watson was nominated by the daughter of a lymphoma patient. She wrote: ‘Even though my dad died, he received great care … and had a hopefulness that carried him through two years of treatment with lots of moments of joy – and Dr Watson is in no small part behind that.’

Maryann MacIntosh

Maryann is a community nurse based in Northern Scotland who covers a vast geographical area. She was nominated by a patient who lives in a remote area of the Scottish Highlands who felt that only with Maryann’s support has she been able to adjust to life post-treatment.

Brian and Jane Crane

Brian and Jane are members of the Norfolk Lymphoma Group (NLG). Although neither has a connection to lymphoma, both Brian and Jane have supported the group and the Lymphoma Association for many years.
The National Cancer Research Institute (NCRI) is a UK-wide partnership between organisations that fund research in the UK and who want to work together to make faster progress against cancer. The lymphoma group held their annual meeting in November 2016.

The meeting was a forum for clinicians to report breaking news on results of clinical trials, to discuss trials open in the UK and to get input on the planning of new trials. A closed session gave a preview of results presented at the American Society of Hematology (ASH) meeting in December. In this article, we summarise some of the breaking news presented at both meetings, and some of the open and upcoming trials discussed.

With thanks to Dr Graham Collins, Consultant Haematologist at Oxford Cancer and Haematology Centre for reviewing this update.
Clinical trials for Hodgkin lymphoma

First-line treatment for classical Hodgkin lymphoma is generally very successful. Many trials now focus on reducing long-term problems after treatment and increasing the proportion of people who respond to first treatment.

- **Euronet-PHL-C2** will test whether more intensive consolidation chemotherapy means radiotherapy can be reduced for children and young people (under 25).

- **RADAR** will test whether replacing bleomycin (which can cause lung problems) in ABVD with brentuximab vedotin (an antibody joined to a chemotherapy drug) can increase the proportion of people who respond to first treatment while reducing side effects.

For people who relapse, the **BEECH** trial is being planned to find out which chemotherapy regimen works best after relapse and who should be given an autologous stem cell transplant.

There is much excitement about newer drugs, particularly brentuximab vedotin and checkpoint inhibitors. Trials are being planned to find out the best time to use these for people with relapsed or refractory classical Hodgkin lymphoma.

Nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) responds very well to treatment but some of the current chemotherapy regimens used can have serious side effects, like infertility and lung problems. A trial testing a lighter touch to treatment has been proposed, with the aim of sparing people with NLPHL these long-term side effects.

Did you know?

You can find out more about clinical trials, including updates and personal experiences at [www.lymphomas.org.uk/LMTrialsLink](http://www.lymphomas.org.uk/LMTrialsLink)

**BREVITY** trial results: brentuximab vedotin gives a high response rate in people who are not well enough for standard treatment – could other treatments make the response last longer?

In this trial, 35 people with classical Hodgkin lymphoma who couldn’t have standard first-line treatment, eg due to heart or lung problems, were treated with brentuximab vedotin alone. More than 8 out of 10 responded to treatment but after an average of 1 year follow-up, the lymphoma had progressed (got worse) in two-thirds of participants. Common side effects included infection, low blood counts and peripheral neuropathy (nerve damage). Trials are being designed to test whether combining brentuximab vedotin with other anti-cancer drugs can improve the duration of response to treatment.

**PAIReD** trial results: an allogeneic stem cell transplant for people who don’t respond to previous chemotherapy gives a high response rate with acceptable side effects.

An autologous stem cell transplant only works well for those who respond well to chemotherapy. The PAIReD trial showed that more than two-thirds of people who don’t respond well to second-line chemotherapy could have a long-lasting remission if they had an allogeneic stem cell transplant. However, not everyone is suitable for such intensive treatment. Newer drugs could allow more people to go into remission and have an autologous stem cell transplant.
GALLIUM trial results: obinutuzumab may be more effective than rituximab in previously untreated follicular lymphoma

The 1,202 participants in this trial were randomised to receive obinutuzumab and chemotherapy followed by obinutuzumab maintenance or rituximab and chemotherapy followed by rituximab maintenance. After 3 years, more people are still alive with their lymphoma under control in the obinutuzumab group compared with the rituximab group. However, more side effects were associated with obinutuzumab than with rituximab. Obinutuzumab could become a new standard treatment for follicular lymphoma but questions remain over what chemotherapy to combine with it and how cost-effective it is.

Waldenström’s macroglobulinaemia (WM)

R2W trial results: bortezomib gives a higher response rate and fewer serious side effects than fludarabine in combination with cyclophosphamide and rituximab (BCR instead of FCR) for people with untreated WM.

Both groups had a high response rate but more people in the BCR group (more than 9 in 10) responded to treatment than in the FCR group (8 in 10). Serious side effects included infection and low blood counts. These were more frequent in the FCR group.

Clinical trials for low-grade non-Hodgkin lymphoma

Follicular lymphoma

Newer antibodies and other newer drugs are making an impact in follicular lymphoma treatment.

The R² combination (lenalidomide and rituximab) is under investigation in ReBel, which is testing R² with or without bendamustine in people with relapsed follicular lymphoma. R² could also help people who don’t respond well to their first treatment. PeTReA is in the planning stages and will test whether rituximab maintenance is needed for people who have a good response to treatment. These people may be able to avoid the side effects of rituximab. It may also compare rituximab maintenance to R² in those who do not respond well.

Mantle cell lymphoma

Although most people with mantle cell lymphoma have an aggressive disease that usually relapses, some have a slower-growing form of the disease. These people may not need immediate treatment or could be treated with less intensive treatments. MCL Biobank is an observational study collecting biopsy samples. The study team compare participants’ progress with factors that might allow doctors to identify people with the less aggressive form of mantle cell lymphoma.

Newer drugs like ibrutinib are improving outcomes for people with mantle cell lymphoma but there may still be a place for allogeneic stem cell transplant for some people at high risk of relapse. Two-thirds of people who had a successful allogeneic stem cell transplant in the mini allo trial were still in remission 2 years after treatment.

Ibrutinib works best when it is used as a first treatment for mantle cell lymphoma. ENRICH is testing whether a chemotherapy-free approach using ibrutinib and rituximab first-line gives a better outcome than chemotherapy and rituximab for older people (over 60) who can’t have a stem cell transplant. For under-60s, the TRIANGLE trial, due to open in 2017, will test intensive chemo-immunotherapy with or without ibrutinib. Participants who have ibrutinib will be randomised to decide if they go on to have an autologous stem cell transplant. The trial aims to show whether ibrutinib improves outcomes and removes the need for a stem cell transplant.
Clinical trials for high-grade non-Hodgkin lymphoma (NHL)

As with other types of lymphoma, newer drugs are a focus of many trials for high-grade NHL, but trials also continue to try to identify which treatment works best for which people.

Diffuse large B-cell lymphoma (DLBCL)

R-CHOP remains the standard treatment for DLBCL but there are several trials exploring the role of newer drugs, when to use radiotherapy and what treatment is best for those who can’t have R-CHOP.

- Results 24 months after treatment in the ReMODl-B trial show that adding bortezomib to R-CHOP made no difference to outcomes for people with DLBCL, even comparing different subtypes of DLBCL.
- lNCA is comparing an antibody-drug conjugate, inotuzumab ozogamicin plus R-CVP with a standard chemo-immunotherapy regimen of gemcitabine plus R-CVP in people who are not fit enough to have R-CHOP.
- TOCH is testing a new drug, vistusertib, alone or in combination with rituximab for relapsed or refractory DLBCL.
- IELSG 42 is testing a new regimen – MARIETTA – for people who have DLBCL in their central nervous system (CNS; brain and spinal cord) at diagnosis.
- ACCEPT opens in 2017 and will test whether adding acalabrutinib (a newer drug that works in a similar way to ibrutinib) to R-CHOP can improve outcomes.
- CONRAD is still being planned but will test whether people with bulky disease (large lumps of lymphoma) who have a good response to R-CHOP need radiotherapy.

Primary mediastinal large B-cell lymphoma

This type of lymphoma most often affects young women. Radiotherapy to the chest carries a risk of late side-effects, like breast cancer. IELSG 37 is testing whether people who respond well to chemo-immunotherapy (PET negative) need radiotherapy.

Primary CNS lymphoma

The MATRIX regimen (thiotepa, rituximab, methotrexate and cytarabine) became standard of care for primary CNS lymphoma when results of the IELSG 32 trial were published in 2016. TIER is now testing whether thiotepa and rituximab with etoposide and ifosfamide can improve outcomes for people with relapsed or refractory primary CNS lymphoma.

Young people with NHL

Practice-changing results: adding rituximab to chemotherapy improves outcomes for children and young people with B-cell lymphoma. Rituximab is added to chemotherapy for most adults with B-cell NHL. An interim analysis of the Inter-B-NHL Ritux 2010 trial showed that adding rituximab can improve the already very good response rate to intensive chemotherapy seen in children and young people. The trial is ongoing to confirm this result and to look at the side effects in more detail, but all participants now have rituximab.

IELSG 32: whole brain radiotherapy (WBRT) and autologous stem cell transplant are both effective consolidation treatments after MATRIX but WBRT may have a greater effect on attention and memory.

After treatment with MATRIX, participants in IELSG 32 were randomised to receive WBRT or an autologous stem cell transplant. After an average of 4 years’ follow-up, there was no difference in survival between the groups. However, attention was significantly reduced in people treated with WBRT and there was a slight decrease in memory function.

T-cell lymphoma

There is a lot of unmet need for people with T-cell lymphoma as it can be difficult to treat successfully. Trials are aiming to answer key questions such as:

- What is the best standard chemotherapy first-line? CHEMO-T is comparing standard chemotherapy, CHOP, with a gemcitabine-based regimen, GEM-P.
- Can newer drugs improve outcomes? RomiCar is testing 2 newer drugs, romidepsin and carfilzomib, in people with relapsed or refractory T-cell lymphoma.

A T-cell Biobank study will be opening in 2017. This will collect samples so researchers can find out more about T-cell lymphoma.
Roger’s experience of a clinical trial for CNS lymphoma

On 7 April 2014 my left arm stopped working. Within a couple of hours it felt fine, but during dinner I suddenly lost the use of my left arm again and dropped my fork. My wife Sarah rang 111 for advice and they asked her to get me to hospital straight away. We were only 10 minutes away but I had a kind of seizure on the way. I remained conscious throughout, but my limbs were jerking and I was thrashing around in the front seat of the car. I couldn’t speak and was struggling to swallow. I was aware of what was happening, but couldn’t do anything about it.

My wife called 999 and tried to keep me calm until the paramedics arrived. I was trying to tell them that I thought I was having a stroke, but my speech was slurred.

At the Emergency Department, I was waiting to be handed over to the stroke nurse when the jerking movements began again. I was fast-tracked for a CT scan. Shortly afterwards they confirmed that this was not a stroke, but a mass on the brain. They started me on steroids immediately and painkillers for the headache. I was told I had a malignant brain tumour and would now come under the Neurological Unit. They scheduled surgery with a view to removing the tumour but this was postponed when they realised the original mass had somehow decreased in size. They weren’t sure why this had happened.

A rare lymphoma

They withdrew my steroid medication and scheduled an appointment 4 weeks later to review the situation, but after just 2 weeks I experienced some minor jerking movements again so the steroids were reinstated and I was admitted to the Neurological Unit for a biopsy. The results revealed that it was not a brain tumour, but a primary CNS (central nervous system) lymphoma. This is a rare type of high-grade B-cell non-Hodgkin lymphoma. I was 48 years old.

I was referred to the Oncology Team at my local hospital and saw the doctor the next day.

The doctor explained the proposed treatment regime, but said there was a clinical trial at a nearby hospital that I may be eligible for. I felt I had nothing to lose!

I saw the trials team 2 days later and after some medical tests to check my suitability, was accepted onto trial IELSG 32 (see page 23 for details of this and other trials). I was randomised to the group receiving intravenous rituximab, methotrexate, cytarabine and an infusion of thiopeta. The cycles were repeated every 21 days for a total of 4 cycles and my progress monitored after each cycle. I began my chemotherapy on the day

To read about the trial Roger entered, go to page 23

To read more visit www.lymphomas.org.uk/CNSLymphoma
that Eleanor Rose, my first granddaughter, was born. I told my wife that I was going to beat this cancer, and take Eleanor to school on her first day. It gave me a real focus. Before treatment started my wife and I had attended a ‘demystifying chemo’ class run by a Lymphoma Nurse Specialist. This had prepared me for how I may feel during treatment, gave us an insight into how chemotherapy affects the immune system and alerted us to the signs of neutropenic sepsis. The first chemotherapy went well and I came home after 6 days. But on the 10th day I felt flu-like. When my temperature reached 38 degrees, Sarah called the hospital. They advised her to get me to A&E quickly where the IV antibiotics I desperately needed were started immediately. I had to stay in hospital for about a week. This happened after every round of chemotherapy, often involving transfusions of blood or platelets.

I had my PICC line removed during the first sepsis episode, as there was a possibility that this was the cause of the infection. Unfortunately, I developed a blood clot in my arm where the PICC line had been, and attempts to put another in were unsuccessful due to my veins collapsing, so I had a central ‘Hickman’ line put in before cycle 2. At least getting dressed was far easier!

Did you know?

**Primary central nervous system lymphoma (PCNSL) is a rare lymphoma affecting the brain and spinal cord.**

It’s slightly more common in men, and in people aged 50-70. Symptoms depend on the area involved, but may include headaches, change in vision, drowsiness, problems with memory or balance, seizures, muscle weakness, changes in personality or problems with speech.

Treatment needs to be planned on an individual basis, but most people have steroids to make the lymphoma shrink. People who are fit enough can be offered chemotherapy, and radiotherapy and a stem cell transplant may be possible. **As CNS lymphoma is rare, you may be cared for at a specialist cancer centre.**
Between the third and fourth cycles of chemotherapy, my stem cells were successfully harvested and stored in case I was randomised for the group that would go on to have additional high dose chemotherapy followed by stem cell transplant. I was, however, randomised to the group that had 1 week of targeted radiotherapy and 4 weeks of whole brain radiotherapy.

A few weeks after the end of treatment, I hit a wall. My consultant had prepared me for this but that didn’t make it any easier. I had no energy or enthusiasm for anything and just wanted to sleep all the time. At the next routine appointment I was re-admitted to hospital for a few days whilst they successfully helped me with the depression.

At the end of treatment my doctor said I was stable and they were very pleased with how things had gone. I had wanted to hear the word ‘cured’, but my doctor explained that because of the nature of the disease, they could not put it in those terms. They emphasised though that everything was looking positive.

Since finishing treatment, I have had ‘chemo fog’, which means that I get confused occasionally. I also get a little depressed, mainly because I had to surrender my driving licence when I had the seizure and cannot drive until 2 years after the end of treatment, which has affected my ability to work. This has put a huge hole in our finances! I went back to work a year to the day after I was taken ill. Although I am on limited duties it really helps me feel I’m moving forward. I get tired more easily, and tend to go to bed earlier these days, but that could just be down to getting older!

My wife Sarah has been brilliant. She stresses the importance of taking each day as it comes and reminds me that everyone can have a ‘bad day’ or forget things. She also says I was hopeless with names when she first met me 30 years ago, so I must stop blaming the cancer treatment!

I try to keep as fit and active as I can and a year after the end of treatment, I completed a 30-mile cycle ride challenge. I have also become a keen gardener, which has helped me to regain most of my strength after treatment.

I feel fortunate to have been given the opportunity to take part in the trial. It encouraged me to find out more about my illness, however scared I was at first. I have no doubt that all cancer patients get excellent care, but the trial nurses are always there if I have any questions. And I am still going to be taking Eleanor to school on her first day in just over 18 months time!’

What you need to know about sepsis

Sepsis is serious, possibly life-threatening and must be treated urgently. The most common sign of sepsis is a raised temperature. If you are having treatment for lymphoma, keep a thermometer handy to measure your temperature accurately. Contact your hospital at once if your temperature is 38 °C or more. Sepsis doesn’t always cause a high temperature though, especially if you’re taking steroids. Symptoms to look out for include:

- a temperature of 38°C or more
- shivering
- chills and sweating
- feeling generally unwell, confused or disorientated
- a cough, sore throat or mouth, earache
- redness or swelling around skin sores, injuries or lines
- diarrhoea
- a burning sensation when passing urine
- unusual vaginal discharge or itching
- stiffness of the neck and difficulty with bright lights.
Information & support

If you, or a loved one, have had a lymphoma diagnosis you might like to talk to someone who understands. Our information and support team is available Monday to Friday 9am-5pm offering information about lymphoma, emotional support and a listening ear.

How to contact us

0808 808 5555

information@lymphomas.org.uk.

www.lymphomas.org.uk/live-chat

www.lymphomas.org.uk/forum

Text us at 07786 202030

WhatsApp: 07494 181130

We’re excited to announce that you can now contact the team during office hours via WhatsApp. Just add Lymphoma Association to the contacts in your mobile phone with the number 07494 181130, open the app and send us a message. If you message us out of office hours we’ll see it on our next working day.

Buddies

If you’d like to talk to someone just like you, we might be able to find you a buddy. Our telephone and email buddies have personal experience of lymphoma and will understand what you’re going through.

Become a buddy

We’re recruiting people to join us as a buddy. Last year we linked around 130 people with buddies, and we’d like your help to support even more. We have demand for patients and carers (eg partners or parents) with the following lymphoma experiences:

✅ watch and wait with no treatment
✅ low-grade non-Hodgkin lymphoma, who have not transformed or had a stem cell transplant
✅ high-grade non-Hodgkin lymphoma who have not had a transplant
✅ Hodgkin lymphoma in their late teens/20s who have not relapsed
✅ mantle cell lymphoma, who have experienced a period of watch and wait before treatment
✅ central nervous system (CNS) lymphoma
✅ chronic lymphocytic leukaemia (CLL) with only one or two treatments
✅ skin lymphoma.

Buddies with rare lymphomas

If you finished treatment at least 6 months ago and would like to be a buddy, we’d love to hear from you. Go to www.lymphomas.or.uk/Buddies or call 0808 808 5555.

Looking for news about Volunteers and Carers week at www.lymphomas.org.uk/LMBlog
Patricia and Kevin had more in common than non-Hodgkin lymphoma. As well as being retired teachers, they have been friends and neighbours for many years.

Patricia was first diagnosed with non-Hodgkin lymphoma in 2010. Four years later she saw Kevin at the hospital following his diagnosis. Patricia was just about to start treatment, having been on ‘watch and wait’, and they found they benefitted from being able to discuss their condition and treatment together.

When other people in the area chatted to them about their lymphoma, they realised that a local support group would be a great idea.

In June 2016, Patricia, Kevin and Karen met to consider:

- Is there a need in the area or is there a group nearby?
- Will the health professional team/clinical nurse specialist support the group and refer new members?
- Is there a free or reasonably priced venue that could be used as a regular meeting place?
- Is there a day and time that would suit most people?

The team at the Countess of Chester Hospital were very supportive and agreed to display posters and hand out flyers. The group began meeting at the Forest Hills Hotel, who now donate a room for a couple of hours once a month. This, together with the support of the Frodsham and Helsby Rotary Club, have enabled the group to be born.

As well as offering support, the group have speakers and presentations that are helpful and informative. Friendships have also developed and some members meet away from the group for a coffee.

Patricia and Kevin are delighted at the group’s success and the support they have received from the Lymphoma Association. Patricia said: ‘It’s good for people to talk to someone other than a doctor - someone who has really been there.’

If you are considering starting a support group in your area and would like to have a chat, contact 0808 808 5555 or go to www.lymphomas.org.uk/SG-Resources
Support groups on the Isle of Man and the Wirral

The first support group on the Isle of Man will be launched in April 2017. The new group will meet at Manx Centre Help, the Lisa Lowe Centre, situated in Cronkbourne. It is about a mile from Nobles Hospital.

For many residents, a diagnosis means a trip across the Irish Sea for hospital visits and there has been no specific lymphoma support service on the island.

We are also launching a new support group on the Wirral peninsula. The group will meet every third Thursday of the month, with the first meeting on Thursday 16 March from 7pm at Tesco Community Space, Bidston Moss.

For more information about our groups, or details of independent groups, call 0808 808 5555, email information@lymphomas.org.uk or visit our website at www.lymphomas.org.uk/LASupportGroups.
Nikie Catchpool, Consultant Occupational Therapist and Macmillan Professional and Joint Clinical Lead at the Bath Centre for Fatigue Services answers some of the most frequently asked questions about cancer-related fatigue.

What is cancer-related fatigue and when is it likely to occur?
Cancer-related fatigue is difficult to define as it is subjective. What is known is that it can affect anyone and at any stage – before diagnosis, during and after treatment.

As a symptom of lymphoma, people may have been struggling with fatigue and it may have been the reason they initially visited their doctor. During treatment, fatigue is better understood, as people are usually advised of it as a potential side effect of treatment.

The time many people struggle with cancer-related fatigue is after their treatment has finished. They see the end of treatment as a real goal – a time to get back to ‘normal’. But fatigue can be very debilitating and may mean plans need to be delayed, which can be difficult. Friends, family and colleagues too may expect everything to be back to ‘normal’ once treatment has finished. Some people avoid mentioning ongoing difficulties, such as cancer-related fatigue, because they don’t want to worry their family, friends or colleagues any further.

Statistics indicate that cancer-related fatigue (CRF) affects up to 9 out of 10 people with cancer.* We’re regularly asked about why fatigue happens, how long it lasts and how best to cope with it.

Talking about cancer-related fatigue

What effect does cancer-related fatigue have?
When we look at how people are managing, we consider 3 areas – self-care (washing, dressing, eating etc), productivity (such as working) and leisure (such as going out with friends).

‘7 months post-treatment (stem cell transplant), it felt like I was still working at about two-thirds power.’

People struggling with cancer-related fatigue often need to prioritise their self-care. Productivity tends to be next on the list of priorities, especially where finances are involved. As a result, leisure is often forfeited when people feel fatigued. The trouble is that by removing leisure you may be taking away support, pleasure and companionship. This can have a real impact on a person’s

* Source: Lymphoma Association, Fatigue, March 2015
To read more visit www.lymphomas.org.uk/Fatigue

‘I have learnt that cleaning the house or gardening requires physical activity and it is not always necessary to go to an exercise class to be physically active.’

quality of life and people may become isolated.

How long does it last?
Not everyone will go on to experience long-standing fatigue. People finishing treatment remember how they used to feel before their diagnosis and see that as their ‘normal’. But it may be helpful to consider a new normal and adapt life accordingly, although this can take some time and adjustment.

Does the stress of a cancer diagnosis contribute to fatigue?
Mind and body are connected, so it is understandable that someone going through cancer will have worries. This can impact on sleep, which can then affect daytime energy levels. In addition, when you are stressed or anxious, your mind can be very active, which takes up a lot of energy. This can make you more fatigued.

What can I do to help with my cancer-related fatigue?
Research suggests that physical activity can help with cancer-related fatigue. This can be any activity, such as walking the dog, gardening, housework or an exercise class.

A key to managing cancer-related fatigue is having a balanced, consistent and sustainable routine. When people have a good day, they are tempted to do more. The trouble is that this often results in the fatigue getting worse. This boom or bust approach is not helpful and can make people feel that fatigue is taking over their life, or taking control away.

Is it helpful to have a nap in the day or should I push through the fatigue?
Mid-treatment a nap may be helpful because your body may need additional rest. But for people who are managing long-term cancer-related fatigue, then napping in the day is not ideal, especially if it affects their ability to sleep at night.

How can I rest my mind as well as my body?
Rest and restorative time can be really helpful, but it is important to rest your mind as well as your body. This may be easier said than done when you are dealing with lymphoma.

You may want to try a relaxation technique, meditation, mindfulness or deep breathing. Ask your medical team if there is a programme available that may be helpful.

Some people struggle to rest because they feel guilty about it. It is best to avoid environments where jobs need to be done, such as a living room that may need to be tidied. Sometimes sitting in the garden with a cup of tea, just noticing the sounds and smells around can be beneficial. Rest and restorative time doesn’t have to be for long periods - it is the quality of the time that is important.
Should I continue working if I am struggling with fatigue?

There are many things to consider, such as finances. If you are employed, you may find it difficult to continue working while undergoing treatment and you may need to adjust your working pattern. For some people, continuing work can be a real focus and coping mechanism. What’s best for each person is individual and should be discussed with your employer.

If you are working and struggling with cancer-related fatigue, speak to your employer and see if adjustments can be made. Reducing your hours may help. If your job is physically demanding, you may want to ask your employer whether a change in tasks is possible. Talk to your employer as soon as possible to avoid worrying about your work situation. You can ask your medical team to write a letter to your employer outlining the difficulties you are experiencing and adjustments that may be helpful.

Are there any medical treatments, alternative therapies or diets that can help?

Unfortunately there are no medical treatments that can help with cancer-related fatigue. Vitamins or supplements can help if you have a nutritional deficiency, such as low iron. Speak with your medical team if you are considering taking any supplements to check it is safe to do so. Many people adjust their diet when undergoing chemotherapy which may be useful. We generally recommend a healthy, balanced diet.

One positive effect of having cancer-related fatigue is that it taught me to be patient.

Turning research into support

The Lymphoma Association is developing strong links with Dutch organisation, the Helen Dowling Institute, which specialises in research and therapeutic support for cancer-related fatigue. Currently the Institute is working on an English-language app for lymphoma. Entitled Tired of Cancer, the app focuses specifically on lymphoma, providing information, learning, tools and resources to help people deal with the impact of their fatigue. This app is still undergoing testing and development, and the Lymphoma Association has helped by recruiting patients to pilot the app and to be part of the research programme. So far, the responses and results have been very promising. For more on the Institute’s work, see www.hdi.nl.
Seeds of hope

The periwinkle is our symbol because part of the flower is used in some chemotherapy drugs given in the treatment of lymphoma.

Buy our limited edition periwinkle seeds to plant in your garden as a symbol of hope and support for people coping with lymphoma, or to give to a friend or colleague to raise awareness of our charity. Seeds should be sown in February or March and will flower between May and August.


The Share Centre

Shares and stockbroker services company The Share Centre supported the Lymphoma Association as their chosen charity throughout 2015 and 2016.

We are delighted that they have raised a total of £11,302 over that time, from numerous fundraising activities ranging from staff quiz nights, raffles, bike rides and office bake sales. Our thanks to all the employees for this wonderful support. If you work for a company and would like to find out how they may be able to support the Lymphoma Association, please drop us an email at fundraising@lymphomas.org.uk

Could you start a fundraising group?

We’re delighted that a new fundraising group has formed in Watford. Over just a couple of months, quizzes, coffee mornings, collections and raffles have already raised nearly £2,000. Thank you to all these volunteers for giving up their time to help others.

We need as many fundraising groups across the country as possible. There are no rules around the number of events or the amount you raise. So please get in touch if you’re interested—we can give you lots of help and support.

Grab your favourite yarn and make a special periwinkle brooch to support Crochet for Cancer.

Anyone can use our periwinkle pattern, whether you have many years of experience or are a complete beginner. Once you have completed your eye-catching periwinkle brooch, sell it to friends and family in return for a small donation to the Lymphoma Association. To download the pattern, go to www.lymphomas.org.uk/Crochet.

For more information about this campaign, email fundraising@lymphomas.org.uk or give us a call on 01296 619419.

Calling all budding crocheters

www.lymphomas.org.uk/GetInvolved

#LymphomaAssoc  lymphomas  www.lymphomas.org.uk

Lymphoma Matters Spring 2017 | 33
Our new Young person’s guide to lymphoma explains what lymphoma is, treatment, side effects, life during and after treatment – including work and study, relationships, follow-up and much more.

This book couldn’t have been produced without a group of young people who have brought the book to life with their quotes, pictures and feedback on the content.

‘I had a lot of questions and concerns about my lymphoma diagnosis and what would happen from here on. I’m sure that young people now affected by lymphatic cancers will benefit from having this resource.

Greg, diagnosed at 23

‘When I was diagnosed with Hodgkin lymphoma the only word I could find to describe the first few weeks was fear. I was completely lost, with information being thrown at me from all directions. I was then given one of the Lymphoma Association’s booklets where everything was set out and explained in a clear fashion, free from all the horror stories I was finding on the internet. This is what this booklet is all about!

Natalia, diagnosed at 20

For a copy of the Young person’s guide to lymphoma, or any other Lymphoma Association information, call 0808 808 5555 or go to www.lymphomas.org.uk/information#booklets
Conferences and events for people affected by lymphoma

Live your Life: living with and beyond lymphoma workshops
We will be running workshops across the UK and we are still looking for further locations for late 2017. Please see our latest news article on page 3.

Joint conferences with Leukaemia Care
Our joint conferences for anyone affected by any of the blood and lymphatic cancers are being held this year in Birmingham (March) and Portsmouth (October).

Lymphoma regional conferences
We are running 4 regional conferences this year in Glasgow, Merseyside, Hull and Belfast. Venues and dates to be confirmed. Please visit our website for further info and to register your interest.

National Conference, 6 May 2017
The UK’s leading event for people affected by lymphoma is being held at Whittlebury Hall, Northamptonshire (see flyer enclosed).

Why not make a weekend of it by taking advantage of our extended package at this 4-star hotel and spa? We would love you to join us for a weekend of support, relaxation and inspiration.
Experience a hidden gem. The Istria Peninsula in northern Croatia is a relatively unknown area which feels a world away from the well-visited Adriatic coast to the south.

Following the Istria Mountain Trail across the peninsula, you trek away from the crowds through from the wooded hills around Buzet east into Učka National Park, where you crest three mountain peaks, culminating in fabulous views over the entire region from the rocky summit of Mount Učka.

There are wonderful mountain views and spectacular stone-walled villages, vineyards and waterfalls and a visit to Hum, the smallest city in the world.

To find out more, email fundraising@lymphomas.org.uk or call us on 01296 619419 – we would love to hear from you.