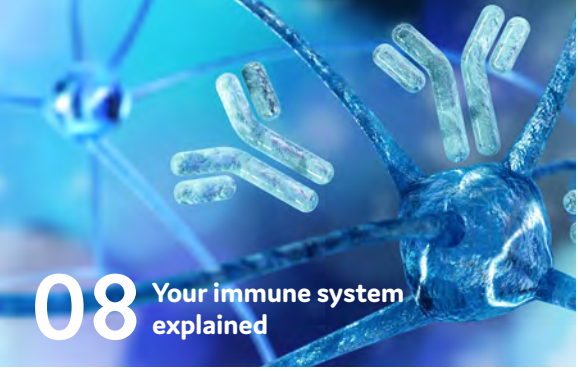
lymphoma matters

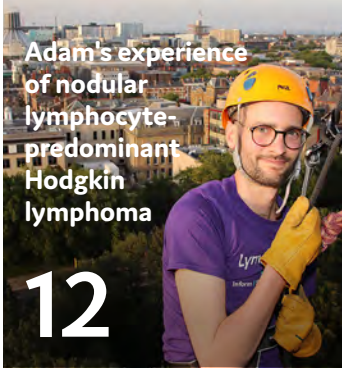
ISSUE 115 | WINTER 2019/20

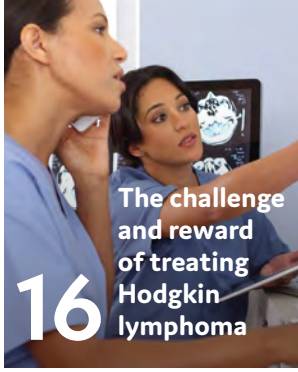
Your immune system

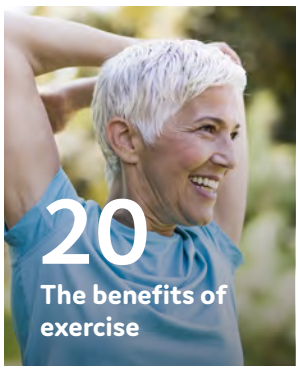
Listen out for Carol on our BBC Radio 4 Appeal

Lymphoma action









Contents

Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among people aged 15 to 24. We've been providing in-depth, expert information and wide-ranging support for over 30 years, helping thousands of people affected by lymphoma. Our work drives improvements in the diagnosis, treatment and aftercare of lymphoma. We're here for you.

Views expressed in this publication are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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

If you would like to make a donation towards our work please visit lymphoma-action.org.uk/Donate or call 01296 619419.

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Lymphoma action

Lymphoma Action is a registered charity in England and Wales (1068395) and in Scotland (SC045850). A company limited by guarantee registered in England and Wales (03518755).

Ropinder Gill,
Chief Executive

Professor John Radford joins us as Honorary President

Read more about our work online in *Our impact in 2018* at lymphoma-action.org.uk/Impact2018

Welcomes, rewards and appeals

Welcome to our winter issue of *Lymphoma Matters*, which I hope you will find interesting and helpful.

We are enormously grateful to the people who generously share their experiences of lymphoma. In this issue you can read Paul, Neil and Adam's stories, all of whom reveal how much a diagnosis of lymphoma has changed their lives.

In this issue I would also like to welcome Professor John Radford as our new Honorary President. As Professor of Oncology at The Christie, John specialises in lymphoma and has a keen interest in research. John takes over the role of President from Professor David Linch who dedicated 28 years to Lymphoma Action before retiring from the role this summer.

Professor Radford has supported us for many years. He has written and reviewed our information, spoken at a number of our conferences and has narrated several videos for us. John has been a long-term member of our Medical Advisory Panel, which he will now chair in his new role.

Professor Radford explained that he is looking forward to his role as President of Lymphoma Action: 'I am really impressed with how well the staff and volunteers work together as a team. It's not a big organisation, but it's having a real impact in terms of improving people's quality of life. And their ethos is the same as my team's at The Christie: that everyone affected by lymphoma should get the best possible information, support, treatment and care.'

John has joined us at a particularly rewarding time. Last month Lymphoma Action received three British Medical Association (BMA) awards in the 2019 BMA Patient Information Awards (see more on page 4) and were voted 'Most Dedicated UK Cancer Charity 2019' in the Global Healthcare and Pharmaceutical Awards.

Finally, on Sunday 3 November at 7.54am and 9.25pm, listen out for Carol who will be sharing her experience of lymphoma on the BBC Radio 4 Appeal. You can also catch up on Thursday 7 November at 3.27pm.

Lymphoma Action wins three 2019 BMA Patient Information Awards

The British Medical Association (BMA) Patient Information Awards were set up to encourage the production of patient information materials that are accessible, evidence-based and well designed.

We are delighted to announce that three of our resources were shortlisted, with two winning first prize in two categories and the other being runner-up in a third category.

Our *Live your Life – living with and beyond lymphoma* workbook, which forms part of our Live your Life programme of workshops, received the first prize in the 'Long-term Conditions' award. Commenting on the resource the BMA reviewer said: '..the way the information is presented, encouraging interactive use by the audience, seems perfect. This thoughtful, practical approach to helping people to help themselves is a major strength of the workbook.'

Our *Clinical trials for lymphoma* booklet received first prize in the 'Decision-making' category and our Easy Read booklet, *Finding out you have lymphoma* was runner-up in the 'Accessibility' category.

Picture above, from left: Athena McCallum (Editor), Vicki Gregory (Senior Medical Writer), Ropinder Gill (CEO) and Lauren Lakritz (Senior Editor)

To access these booklets and other information free of charge, either download or go online to lymphoma-action.org.uk/Shop

Pushing for better access to CAR T-cell therapy

Lymphoma Action are working with other organisations to continually push for improvements in the availability and delivery of CAR T-cell therapy to allow everybody who is suitable for treatment to access it. We have written to NHS England to express concern about the current commissioning arrangement.

Although CAR T-cell therapy is approved for use on the NHS in England and Wales, at present there are only seven centres in the UK licensed to provide this therapy for lymphoma, because it can only be given in hospitals with the facilities and staff to deliver it safely and manage the potentially serious side effects.

This means there are large geographical regions without a designated delivery centre. Therefore eligible patients are referred out of their region, which can involve travelling long distances and staying away from home which may impact on the patient experience. This can also add an additional financial burden which may be a barrier for some.

There are also limited manufacturing sites that carry out the genetic modification required to make CAR T-cells. At the moment, these are all in the USA, which means there is worldwide competition for 'manufacturing slots' that could lead to delays in treatment.

So far all eligible patients referred for CAR T-cell therapy in the UK have had access to treatment, but we will continue to monitor the situation – especially if the number of patients who are eligible increases as we anticipate.

Lymphoma Action welcomes new trustees

We are delighted to welcome Keith, Sarah and David, who bring a wealth of knowledge to the charity.

Keith McLeod has joined as our Trustee and Treasurer, having spent the last 30 years working as a chartered accountant in the financial services sector. **Sarah Wells** is a lymphoma clinical nurse specialist (CNS) at The Christie Hospital in Manchester and as a key worker for all lymphoma patients will provide invaluable insight. **David McNeill** was treated for Hodgkin lymphoma over 20 years ago and has since lived a healthy and active life, most recently working in public affairs and communications. As David says: 'It is both a privilege and a joy to become a trustee of Lymphoma Action. I hope to bring my professional experience in communications and my personal experience of lymphoma to support the organisation, as it builds on its many achievements'.

Trustee, Sarah Wells

Trustee and Treasurer, Keith McCleod

Trustee, David McNeill

New information now available

Written by medical writers, approved by experts and reviewed by people affected by lymphoma, our information is revised every 3 years.

Here is some of the information that has been written in the last couple of months. Find them at lymphoma-action.org.uk/Publications

- Bereavement and grief
- Biopsy
- Bowel problems
- Clinical trials
- Communicating with people around you
- Diet and nutrition
- Diffuse large B-cell lymphoma
- Emotional impact of lymphoma
- Having a stem cell transplant
- Relationships, family, friends
- Specific information on T-cell lymphomas.

Seeking people to get involved in a booklet for carers

Do you support a parent, friend or relative with lymphoma? We're planning to produce a booklet to help with the practical and emotional aspects of caring. Please get in touch if you can share your story, help with ideas or review a draft by emailing Lauren at **L.Lakritz@lymphoma-action.org.uk**

Lymphoma TrialsLink!

Our clinical trials information service is 3 years old. If you haven't visited Lymphoma TrialsLink before, why not take a look?

You can find out more about clinical trials for lymphoma, or search for a trial that might be suitable for you. We currently have over 65 open lymphoma trials on our online searchable database. You can also read personal experiences of people who have taken part in a trial or read the latest news in lymphoma research.

If you've already used Lymphoma TrialsLink, we'd really like to know what you think. Did you find what you were looking for, and if so, what did you do with the information? We're also keen to hear any suggestions for how we can improve the service. Let us know at **trialslink@lymphoma-action.org.uk**

Listen out for Carol

...who is sharing her experience of lymphoma on the BBC Radio 4 Appeal on Sunday 3 November at 7.54am and 9.25pm. You can also catch her on Thursday 7 November at 3.27pm.

A BBC RADIO 4 APPEAL

NOVEMBER

Christmas cards

It's time to mention Christmas!

This year's range of Christmas cards is even bigger and better than ever. They are available now from our website **lymphoma-action.org.uk/Christmas**

If you don't want to buy Christmas cards, why not make Christmas cards and sell to your friends? Our supporter Shirley has raised over £3,000 selling homemade cards.

DECEMBER

Hold a purple party

Go purple for lymphoma this Christmas and invite your friends round. It can be anything from a purple coffee morning to a purple pamper party.

Christmas Concert in Ormskirk

Ormskirk Rock Choir will be performing on Thursday 5 December at 7.30pm at Christ Church Ministry Centre, Aughton. It promises to be fun and upbeat with a Christmassy twist. **Tickets are available online lymphoma-action.org.uk/OrmskirkRockChoir or call 01296 619419.**

JANUARY

Jump into action!

Join Team Lymphoma in 2020 for one of our exciting challenge events. Whether you are interested in running, cycling, ultra-challenges or a skydive we have an event suited just for you. **lymphoma-action.org.uk/JumpIntoJan**

FEBRUARY

Themed evenings

Get warm and cosy and have a night in for us – hold a board games evening, pamper party or film night and raise valuable funds at the same time. **Email fundraising@lymphoma-action.org.uk for a full fundraising pack.**

Save the date – Saturday 9 May 2020

Andrew Samuel is holding a Gala Dinner for us in Glasgow at the Grand Central Hotel. Tickets are £65, available at **lymphoma-action.org.uk/Glasgow**.

Join Team Lymphoma on the same day and take on the fastest **zip line** in the world. Whizz through the air at over 100mph above breathtaking views at Penrhyn Quarry. **For more information on either of these call Sarah on 01296 619435.**

YOUR IMMUNE SYSTEM

and how it is connected to lymphoma

If you have been diagnosed with lymphoma, you are likely to have heard a lot about the immune system.

It is connected to your lymphoma. It is increasingly being used in new drugs such as antibody therapies, targeted drugs and CAR T-cell therapy. It is discussed during treatment, especially if you have 'a compromised immune system'.

So, with all this talk about the immune system, we thought it would be helpful to give an overview of what it is, how it works and how it is connected to lymphoma.

Your immune system protects your body against infection and diseases, including cancer. It recognises the cells that belong to your body and tries to get rid of anything that shouldn't be there in case it causes you harm. This includes germs (bacteria, viruses and parasites) and toxins. Your immune system also helps to destroy any of your cells that are old, damaged or have become abnormal.

There are different parts of your immune system, which work in different ways. In particular, you have 'innate immunity', which you are born with, and 'acquired immunity', which develops throughout your life as you get exposed to infections.

Innate immunity

The innate immunity you are born with includes physical barriers and phagocytes, which are types of immune cell that can fight many different types of infection and disease.

Physical barriers prevent organisms getting into your body and are the first-line of protection against infection. They include:

- Your skin, which not only acts as a barrier, but also produces oils that can help kill germs.
- Mucosa, which is the soft, moist lining in certain areas of the body, such as your mouth, nose, gut and breathing passages that can trap germs. Mucosa are coated with mucus, which contains proteins and immune cells to attack and destroy these germs. Fluids, such as tears and saliva can wash away germs on the mucosa.
- Your stomach acid helps to destroy any germs that you swallow.

Increasingly, lymphoma treatments are using the immune system to help treat the lymphoma.

Immune cells

If a germ gets past your body's physical barriers, you have lots of immune cells to fight infection. There are different types of immune cells, most of which are types of white blood cell. Immune cells can be divided into phagocytes and lymphocytes. Of these, lymphocytes belong to the acquired immunity system (see later).

Phagocytes can 'eat' or destroy germs and any of your own cells that are no longer useful to your body. There are several different types of phagocytes including macrophages and neutrophils.

Macrophages develop from white blood cells called 'monocytes'. They also 'eat' germs and dead, old or abnormal cells, but can only deal with small numbers of cells. When needed, macrophages use chemical messages to signal for help from other immune cells.

Neutrophils are found in your bone marrow and bloodstream but move into tissues if there is an infection or if tissue repair is needed. Like microphages, they kill and destroy germs, particularly fungi and bacteria, and send out more signals to bring other immune cells to the area.

Acquired immunity

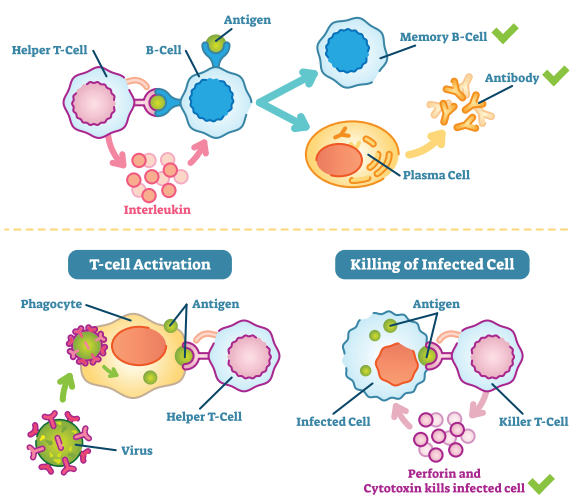
You develop acquired immunity throughout your life as you get exposed to particular infections. This type of immunity is specific to those infections and prevents you getting the same infections again.

Vaccinations expose you to a small dose or inactivated form of an infection so that your immune system can recognise it in future.

Introducing lymphocytes and antibodies

Lymphocytes are a type of white blood cell that is important for

B-Cells and T-Cells



When a cancer develops, it means the immune system has not detected the cancerous cells or has not been able to get rid of them.

acquired immunity. You have B lymphocytes and T lymphocytes. They 'remember' infections you have had before so that your body can produce lots of immune cells very quickly if you are exposed to the same infection again. Lymphocytes are the immune cells that become abnormal in lymphoma.

B lymphocytes (B cells)

B cells are made in the bone marrow but live mainly in lymph nodes and other lymphatic tissues, such as the spleen.

After they've come into contact with an infection, B cells can turn into **plasma cells**, which can produce a huge range of antibodies (proteins that are also known as 'immunoglobulins'). Antibodies fight infection by sticking to proteins on the surface of organisms. These invading proteins are known as 'antigens'. Each B cell can react to only one type of antigen. If a B cell is triggered by contact with its specific antigen, it quickly makes copies of itself. These copies can turn into plasma cells and produce large amounts of antibodies. These fight infection by:

- directly stopping the germ from breaking into our cells
- telling other immune cells (for example, macrophages and neutrophils) that the cell should be destroyed, switching on proteins called 'complement' to destroy the cells
- sticking to toxins and stopping them doing any harm.

Once the infection has gone, most of the B cells and plasma cells that have been produced in response to the infection die. A few plasma cells remain in the bone marrow for much longer, making antibodies to protect against future infection. A few B cells continue to live in lymph nodes. These can respond again more quickly to the same infection if needed – they are known as memory B cells.

T lymphocytes (T cells)

T cells are made in the bone marrow but develop fully in the thymus, before moving to live in lymph nodes. Your own cells 'show' antigens to T cells.

Like B cells, each T cell can recognise just one type of antigen. If it comes into contact with that antigen, it makes copies of itself, but unlike B cells, they do not produce antibodies. Instead new cells then become various special types of T cell that work in different ways:

- **Cytotoxic T cells** kill the germ, particularly viruses and tuberculosis (TB) bacteria. They also look out for any of your own cells that might be 'going wrong' (such as becoming a cancer cell) and kill them too.
- **Helper T cells** support the fight against infection by telling B cells to make more antibodies and by 'switching on' more macrophages and neutrophils.
- **Memory T cells** are left behind once the infection has gone – only a few of them are needed. They allow the immune system to respond quickly if the same infection starts again.
- **NK cells** (natural killer cells) are like T cells, except that they do not develop in the thymus. They don't need to be activated by an antigen but recognise signals from your own cells that tell NK cells not to kill them. They kill cells that have been infected by a virus or are turning into cancer.

Immune cells and proteins that help lymphocytes

There are other immune cells and proteins which are part of your immune system. These include:

- **Dendritic cells** which help direct the work of both B cells and T cells.
- **Histiocytes** which stay in one place in the tissues rather than circulating around the body. They can also tell the lymphocytes that an infection is present.
- **Complement**, a group of proteins that are made in the liver and found in the bloodstream. They can join together and stick to a germ and either punch holes in it or burst it, or signal to macrophages to 'eat' it.

What can go wrong with the immune system?

The immune system does not always work perfectly. It might over-react, causing allergies and autoimmune conditions. It might not work as well as it should, causing immunodeficiency. Sometimes the immune system does not recognise abnormal cells, which can allow cancer to develop.

The immune system and cancer

As well as protecting you from invading viruses, fungi and bacteria, your immune system should also protect you from your own cells if they go wrong.

When a cancer such as lymphoma develops, it means that the immune system has not detected the cancerous cells or has not been able to get rid of them. This does not always mean that the immune system is weak. Often it happens because the cancerous cells look like normal cells on the surface. They don't stand out and therefore are not detected by the immune system and are able to grow. Cancer cells also develop ways to prevent the immune system attacking them. For example, some cancer cells make special proteins on their surface that tell T cells not to attack them.

Your immune system after treatment for lymphoma

Many cancer treatments affect the immune system. Treatments for lymphoma aim to kill the cancerous lymphocytes but they also kill some of your body's healthy cells, including your immune cells. That is why your medical team will recommend you avoid crowds or situations which will increase your risk of infection.

Over time your immune system should recover after your treatment for lymphoma. Most people who have recovered after standard treatment for lymphoma and are in remission are not at increased risk of infection. However, some treatment can have longer-term or permanent effects on the immune system, such as a splenectomy or stem cell transplants.

Increasingly, lymphoma treatments are using the immune system to help treat the lymphoma. These include antibody therapy, allogeneic stem cell transplants, targeted drugs, and CAR T-cell therapy.

With thanks to Dr Toby Eyre, Consultant Haematologist at The Churchill Hospital, Oxford for reviewing this article.

SUDDENLY I'M NOT INVINCIBLE

Adam talks about his diagnosis of nodular lymphocyte-predominant Hodgkin lymphoma

At 27, I had a dog-walking business and worked part-time in retail. I was fit and active – not only walking dogs for around 2 hours a day, but also regularly playing football and swimming, and travelling as much as money and time would allow.

About 4 years beforehand, I had noticed a lump in my armpit and had been to my GP. At the time, he reassured me it was fatty tissue. Although the lump didn't go, I ignored it. That was until July 2018, when I noticed the lump suddenly get a lot larger. I also noticed lumps in my neck and chest, and the right hand side of my chest looked like it was curving inwards.

I didn't feel ill and was just getting on with my busy life, but this change worried me so I went back to the GP.

As soon as I lifted my arm up, he told me that he was going to refer me to hospital straightaway. This was the start of a couple of months of tests, including X-rays, ultrasound and MRI scans, numerous blood tests and ultimately a biopsy.

Like many people in their 20s, I thought I was invincible. I never thought anything could be seriously wrong. So I was totally shocked when I was told I had nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL) stage 3, a slow growing type of lymphoma. It took a while to sink in that I had cancer.

I really didn't want to go through treatment, but I knew I had no choice.

But in a weird way, I also felt a bit of relief, because now I knew what the lump was.

Things moved really quickly after that. I was introduced

to the haematology team who explained that because NLPHL is a slow-growing type of lymphoma, they would need to assess whether I needed treatment straightaway or whether I would have a period of active monitoring (watch and wait). A PET scan revealed that the lymphoma was at a stage where treatment was needed, so in October 2018 I was told that I would need six cycles of R-ABVD chemotherapy, and growth factor G-CSF for 5 days starting 4 days after each chemotherapy.

In a weird way, I felt a bit of relief because now I knew what the lump was.

I felt that my life was on hold and I no longer had control over it.

I told very few people. I felt embarrassed to tell my friends, so only told my family and my manager at work. My parents, brother and sisters were really supportive and my dad went to all the treatments with me.

When I went in for my first treatment on 2 October 2018, I really didn't want to go through with it. It felt like this was happening to someone else. But I knew I had no choice, so got on with it.

Treatment wasn't as bad as I thought it would be. I got away with relatively few side effects, and only remember feeling sick once. I started to lose my eyebrows and leg hair but was glad that my hair and beard didn't fall out completely. The things that were the most problematic were constipation and insomnia. In fact, it was the growth factor G-CSF that caused the most trouble, causing really bad hip and back pain, although even that improved over time.

Even on bad days, I had to take the dogs out, which helped me physically and emotionally.

Physically I was acting like nothing was wrong and I was trying to keep things as normal as possible. I continued to walk the dogs, although looking back, I think it was the dogs that were walking me!

I had still not told my work colleagues, and they were asking questions about why I was off. I didn't feel ready or able to tell them at the time, so made excuses like I had things to take care of and that I would be back at work soon.

I had a scan booked for 22 November. I was surprised at how quickly this had come up as, at that point, I had only had three cycles of treatment. But that scan was really reassuring as it indicated that I was responding to the treatment.

Would you like to do an abseil like Adam? Go to **lymphoma-action.org.uk/Challenge**

In February I developed a high temperature. My mum noticed I was looking red and I had no energy. Just having a shower was talking all my strength. We realised that this was a red flag moment and that I needed to get straight to hospital.

I had developed neutropenic sepsis and needed to be treated with antibiotics and G-CSF injections to help my neutrophil count recover faster. I was in hospital for a week and my next chemotherapy was delayed.

I had six cycles of chemotherapy over a 6 month period, and had another scan at the end. The scan came back clear. I remember crying when I heard the news. It was such a relief for me and for my family.

I returned to work 10 days after my last treatment. I'm fairly sure that the dog walking helped me recover more rapidly. Even on bad days I had to take the dogs out, which helped keep my fitness up, and probably helped with potential fatigue. They were always so pleased to see me and they stopped me from thinking too much about the lymphoma. They really made me feel much better.

I get frustrated with people moaning about silly things.

Looking back, I can barely believe what has happened to me in the past year. My perspective on life has changed so much. I get frustrated with reality TV and all the moaning about silly things. This annoys me in a way it never had before.

I have gone back to playing football and have taken up badminton as a new sport.

When I was first diagnosed, I wanted to keep it to myself, but now I think it is important to learn as much as I can about lymphoma and to raise awareness of it. I went to the Lymphoma Action Conference in May which I found really interesting and helpful and attend a support group locally.

I have always been a keen traveller and try to book as many trips as I can. I finished treatment in March and went to Israel 6 weeks later, then Sweden followed by New Zealand.

Now that I have finished treatment, I am really keen to give something back and I did a sponsored abseil down Liverpool Cathedral in August.

Adam

Did you know?

Around 1 in 20 cases of Hodgkin lymphoma are nodular lymphocyte-predominant Hodgkin lymphoma (NLPHL).

NLPHL affects more men than women and often affects people in their 30s to 50s. There are around 200 cases diagnosed in the UK each year.

Treatment for this rare, slow-growing type of lymphoma is usually very successful.

Find out more at lymphoma-action.org.uk/NLPHL

Step into 2020 and beyond

It's going to be the year for walking!

Join Team Lymphoma for fantastic walks and help ensure no one has to face their lymphoma alone.

June 2020 Bridges of London

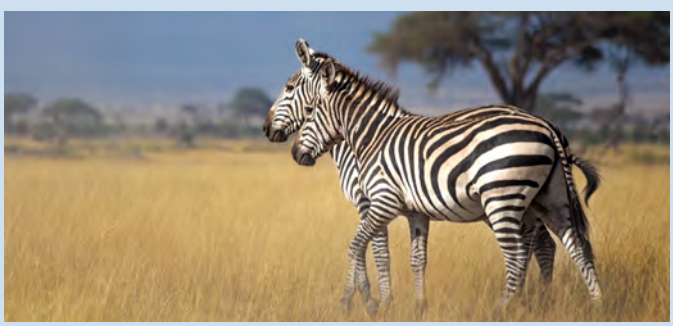
2019 saw our first Bridges of London Walk which had over 351 participants who raised an amazing £40,000 towards our work. We'd like to make 2020 even bigger and better. This walk is suitable for all ages and is a real family day, so gather everyone together and join us on Sunday 7 June 2020.

March 2021 Kenya's Great Rift Valley!

This is a Lymphoma Action bespoke trek and a challenge of a lifetime. Fully supported by trained expedition leaders and Masai guides, you will trek across the grasslands, valleys, hills, volcanoes and gullies of the Great Rift Valley. Stay in local villages as you progress on your travels and enjoy the stunning flora, fauna and vistas as well as the great wildlife.

Contact Adele in the Fundraising Team for more information on 01296 619413.

The cost of this trip is £3,250 per person which includes all flights, food, and accommodation and a donation. We can support you if you plan to fundraise for this trek. Places are limited to only 15, on a first come first served basis.



Stock photo

The challenges and rewards of treating Hodgkin lymphoma

At our National Conference in London's County Hall on 11 May, Dr Kate Cwynarski shared the challenges and rewards of treating people with Hodgkin lymphoma.

Hodgkin lymphoma often has an excellent outcome. Treatment aims to cure the disease, which is very rewarding. However, choosing the right treatment for each individual can be complicated and challenging. The aim is to choose the treatment with the highest chance of cure and lowest chance of side effects (toxicities) for each person – but that can be a lot harder than it sounds.

Hodgkin lymphoma is generally treated according to whether it is early or advanced stage. When early stage, this is further subdivided into whether there are 'favourable' or 'unfavourable' features. However, within the international community, there are some differences in the criteria used to define 'favourable' and 'unfavourable'. This can make it difficult to compare the results of clinical trials and to decide on the best treatment for each individual.

Early stage, favourable Hodgkin lymphoma

For early stage, favourable Hodgkin lymphoma, treatment often consists of abbreviated courses of chemotherapy (usually ABVD to start) followed, for most people, by radiotherapy. This is highly effective therapy.

The recommendation is to consider radiotherapy after abbreviated chemotherapy unless there are strong reasons to avoid it. In this setting further chemotherapy courses may be considered instead. This involves discussion with the haemo-oncologist and clinical oncologist where the potential benefits and toxicities of chemotherapy

Stock photo of PET scan

and radiotherapy can be outlined.

Early stage, unfavourable Hodgkin lymphoma

Early stage, unfavourable Hodgkin lymphoma might be treated with more cycles of ABVD or involve a chemotherapy regimen called escBEACOPP (or escBEACOPDac), often with radiotherapy. A PET scan after two ABVD treatment cycles can help decide which further chemotherapy regimen is recommended (continuing ABVD or increasing the intensity to escBEACOPP or escBEACOPDac). Again, radiotherapy can be incorporated into the treatment plan after discussion with a clinical oncologist.

Advanced stage Hodgkin lymphoma

Advanced stage classical Hodgkin lymphoma is usually treated with either ABVD or escBEACOPP (or escBEACOPDac) chemotherapy regimens.

Both treatments have advantages and disadvantages and there is no overall consensus on which is better:

- escBEACOPP or escBEACOPDac tends to produce better short-term outcomes but it has a higher risk of long-term complications and potential effects on quality of life
- ABVD has a lower risk of long-term complications and is generally better tolerated than escBEACOPP, but it has a lower response rate.

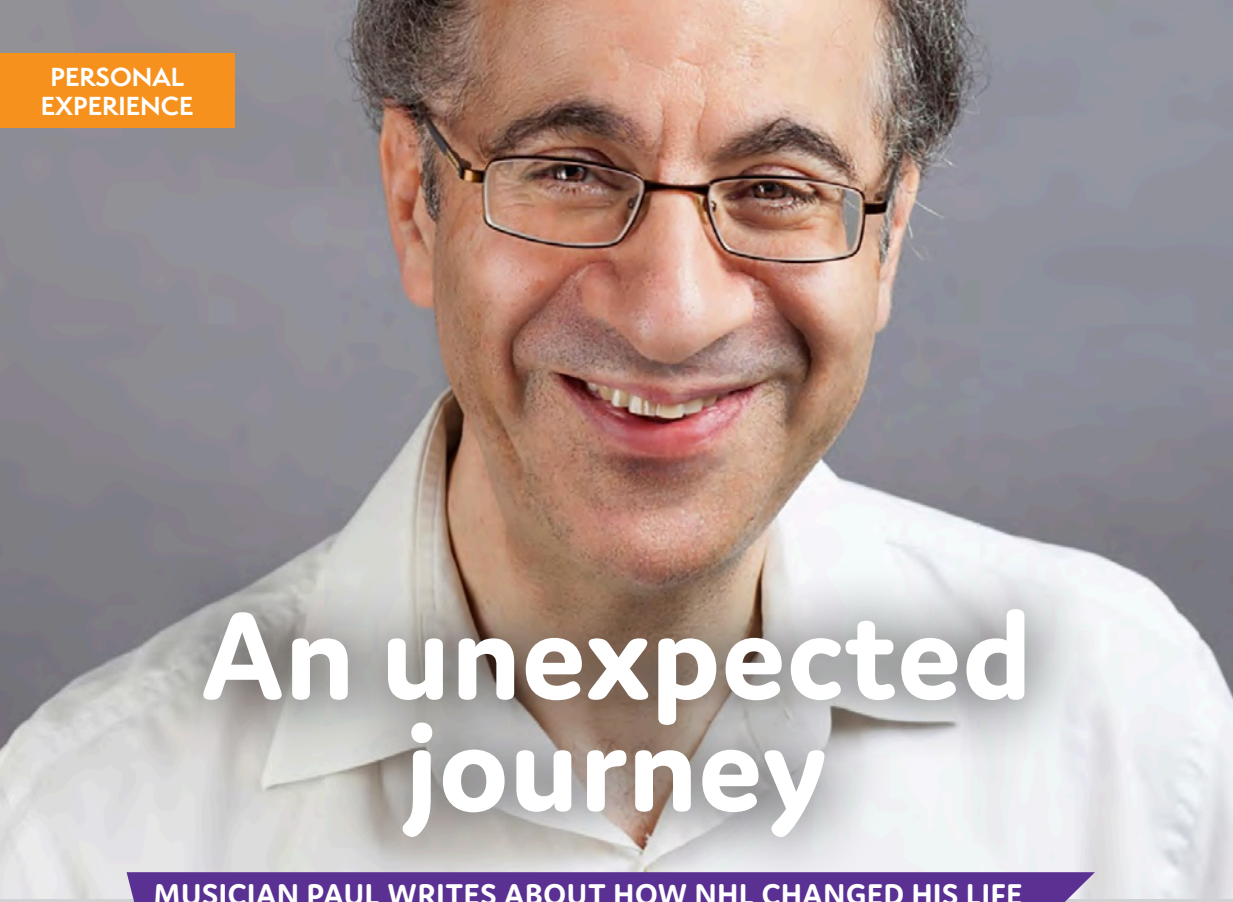
Treatment can be adjusted based on the results of a PET scan after two treatment cycles – but the decision on whether to start with ABVD and escalate to escBEACOPP (or escBEACOPDac) for people with a positive interim PET scan, or start with escBEACOPP (or escBEACOPDac), can be challenging and involves discussion with the patient and their treating team.

Treatment can be adjusted based on the results of a PET scan.

'Our aim is to cure our patients with Hodgkin lymphoma with the minimum therapy possible. However there is a fine balance between potential risks and benefits of the different treatments available. Predicting who will benefit from more intensive treatment up-front – and who can be successfully treated without being exposed to more toxic therapy – is challenging.'

Dr Kate Cwynarski, Consultant Haematologist, University College London Hospital.

The aim is to choose the treatment with the highest chance of cure and lowest chance of side effects.



An unexpected journey

MUSICIAN PAUL WRITES ABOUT HOW NHL CHANGED HIS LIFE

It was a little over 2 months since that first appointment at my local surgery. I had been experiencing some rather vague abdominal pains and thought they ought to be checked out. Until that point, serious illness had never been part of my life.

Now I was sitting opposite a consultant having been through scans, biopsies and blood tests. 'You have high-grade non-Hodgkin lymphoma'. She went on to explain a lot about lymphoma and the 6 months or so of treatment, but most of it passed me by. Words like 'cancer' and 'tumour' are very powerful and seem to reverberate in the mind, reducing all else to a fog.

As a musician and teacher who spends much of life presenting masterclasses and concerts, delivering workshops and teaching, the forthcoming chemotherapy, with its enforced isolation – no visits to public places or travel on public transport in case of life-threatening infection – made me feel very uneasy.

The first chemo hit like a sledgehammer. It took 7 and a half hours to pump in all the drugs – some by syringe and some drip fed into my PICC line. I had taken books and my computer with me,

I spoke openly about my cancer. It makes conversations so much easier. No one is in any doubt about what, or what not to talk about.

but made use of neither. The experience was all-consuming and took me to a place I had never been before.

I had a very useful conversation with a friend who had come through his own cancer experience. He told me to concentrate on three things:

Exercise – something I had been feeling too weak to do, but now made a special effort to find the energy for.

Eat well – I'd had virtually no appetite for some time and had lost a lot of weight, but now made a major attempt to eat more nourishing foods.

Be positive – although I am positive by nature, I decided to be even more positive.

Happily, the cabin fever, the anger, and the loss of direction began to recede. I felt better.

I also decided to share my cancer with all those close to me, and spoke openly about what I was going through. It makes conversation so much easier. No one is in any doubt about what, or what not to talk about. It's the side effects that you spend most time having to deal with. While on the one hand, the cocktail of chemicals are hopefully doing their job defeating the cancer, on the other, they are presenting you with problem after problem. Many are unexpected – even if you are expecting them. Sickness, lack of sleep, bad taste in the mouth, hair fall-out, numbness in toes, dizziness and, the worst by far, constipation. But you learn, in my case with the help of my wonderful GP, how to control them.

Treatment presents problem after problem. Many are unexpected – even if you are expecting them.

During the 6 months of treatment I managed to compose many pieces of music, carry on giving lessons to my healthy pupils (infected ones were not allowed!) and I wrote a number of my music teaching workbooks.

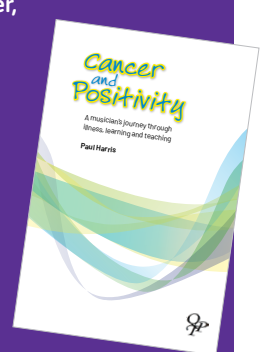
I wasn't going to let the cancer block my creativity.

There were quite a number of low periods – but what struck me was that through the whole experience I was constantly learning. Dealing with the illness, sharing the experience with my friends and putting myself, unconditionally, into the care of all the exceptional medics caused me to learn so much. About empathy, about isolation, about fear, about how we say things, about gratitude, about patience, about expectations. Above all I've learnt to take nothing for granted.

My treatment ended last September and all looks to be well. But I'm not quite the same person I was. There's nothing desirable about cancer. But for me, I worry less, I get more frustrated when I witness behaviour that is unkind or unjust and I try not to waste opportunities.

Paul

Paul Harris is a clarinetist, teacher, composer, author and one of the UK's leading music educationalists. In 2018 he was diagnosed with non-Hodgkin lymphoma. He kept a journal which has been published, *Cancer and Positivity, A musician's journey through illness, learning and teaching*, (Queen's Temple Publications, ISBN 9780955247385). Available at **qtpublications.co.uk**. All proceeds to Lymphoma Action and the Churchill Hospital charity. Our thanks to Paul for his generosity.



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THE BEST PROJECT YOU WILL EVER WORK ON IS YOU!

There is compelling evidence that exercise during and after treatment for lymphoma can improve your physical and mental wellbeing.

Gemma Hillier-Moses shares tips on how to make movement, physical activity and exercise part of your daily life.

After a diagnosis and treatment for lymphoma you may feel a loss of control. But movement, physical activity and exercise is something that gives you a sense of control and normality. It also provides many physical and psychological benefits.

Your reality after a lymphoma diagnosis and treatment may include cancer-related fatigue, loss of physical strength, depression and anxiety, weight loss or weight gain, body image issues, pain, nerve damage and reduced bone density to name but a few. At times it can feel a challenge just to get out of bed.

However the current evidence base for cancer survivorship strongly advocates participation in physical activity, with the National Cancer Survivorship Initiative stating:

'There is persuasive evidence that a healthy lifestyle during and after cancer is associated with improved physical and psychological wellbeing'.

Moving more when you can, has been shown to:

- reduce the risk of side effects during treatment
- improve symptoms of cancer-related fatigue
- prevent loss of bone mineral density and muscular strength
- control body weight
- reduce the risk of other co-morbidities such as diabetes
- improve quality of life
- improve mental wellbeing.

How do I start?

Set yourself a goal. Everyone will have a different goal. It helps you to keep motivated and accountable. The goal depends on the diagnosis, the treatment you have had, any side effects you have, any pre-existing conditions, your age, your general fitness and many other factors.

Don't be tempted to compare yourself with others.

Try and overcome barriers:

Try and overcome barriers

- ✗ I'll start next week
- ✗ I feel embarrassed
- ✗ I would go out today, but it's raining
- ✗ I'm not a gym person
- ✗ I don't have the time
- ✗ I don't know where to start
- ✗ I'm way too tired.

Focus on some of the motivators:

- ✓ I can arrange to do exercise with family and friends
- ✓ I will have some 'me' time
- ✓ I may meet new people
- ✓ It's a chance to get out
- ✓ It will improve my strength and fitness
- ✓ Let's see if I still can
- ✓ It will improve my mental health
- ✓ I can take the first step
- ✓ I'm going to find something I enjoy
- ✓ Reducing sitting time and moving a little more really counts.

TOP TIPS to get started

Talk to your medical team about your plans and discuss the type of exercise that will be best for you.

- Set goals
- Do things you enjoy
- Work with your team to create a plan that's right for you
- Keep it simple and achievable
- Build up gradually
- Find out what works for you
- Get into a routine
- Work on reducing sitting time
- Schedule exercise into your day
- Involve family and friends
- Make sure you relax and recover after exercise
- Listen to your body.

Don't forget that gardening, cleaning the car and walking the dog are all excellent ways to exercise. Just standing and moving around is helping your heart. There are also new resources from the Moving Medicine team that you can take a look at. Search **movingmedicine.ac.uk**

With thanks to Gemma Hillier-Moses, MOVE Founder and Cancer Rehab specialist. Gemma was diagnosed with Burkitt lymphoma in 2012 and following treatment started a charity called MOVE (www.movecharity.org). Look out for a 5k Your Way, Move Against Cancer group near you (www.5kyourway.org).

If exercise was made into a pill, everyone with a lymphoma diagnosis would be taking it.

The Clinical Oncology Society of Australia, as seen in *The Guardian* news article.

‘Would I take the winnings from the EuroMillions or a clear PET scan?’

‘A clear PET scan any day!’

Neil talks about his diagnosis of grey zone lymphoma

In 2016 I was 51 and working in the pharmaceutical industry. I am a chemist by profession with knowledge of drugs, the way they are tested and manufactured. So was this an advantage in my case? Well, it was a bit more complicated than that.

At the beginning of 2016 I had a minor cough. It wasn’t really troubling me and I was still able to run 4 miles twice a week and cycle. By April my cough was getting worse, and I noticed that I needed to cough at the end of almost every sentence.

I went to see my GP, and felt that I might be troubled by stomach acid. I was prescribed some antacid and he said to make another appointment if it didn’t work. After no improvement I did as he said and went back, something I am so glad I did! He arranged for me to have an X-ray as a precaution.

The X-ray showed a 5cm mass above my right lung, which was likely to be cancer. In truth I was not surprised as the antacid had done nothing and I realised that somehow I didn't feel generally well and was fatigued. Suddenly I became an impatient person. I wanted an accurate diagnosis as soon as possible; I wanted to start treatment as soon as possible. I kept asking what I could do to speed things up.

By the end of the first week, I was having a CT-guided needle lung biopsy. Everything seemed to be moving along. Then everything went quiet and there was the waiting, which anyone who has had a lymphoma diagnosis will understand.

I had to wait 2 weeks before seeing a consultant haematologist. He explained that I had lymphoma, but that it was complicated. My case had been discussed at a multidisciplinary team (MDT) meeting and while most of the cells coming back from the biopsy were diffuse large B-cell-like, in the middle there were also Reed-Sternberg-like cells that are present in Hodgkin lymphoma.

My diagnosis was grey zone lymphoma, stage 2E. I had features of diffuse large B-cell lymphoma and classical Hodgkin lymphoma.

My doctor explained my treatment would be six cycles of R-CHOP chemotherapy, probably followed by radiotherapy.

It helped me to know that nothing I had done had caused the lymphoma.

I decided to throw myself into exercise. I wanted to be as fit as I could to manage the treatment, and as robust as possible to give myself the best chance. I also tried to mentally prepare myself for the biggest challenge of my life.

As things were looking up, I knew the next treatment wasn't far off.

I had started out feeling shocked and angry. I had kept myself fit and had never smoked. But understanding that nothing I had done had caused this helped.

My daughters were 18 and 19 at the time, so I decided to be honest with them and tell them everything. They coped well, although I noticed my younger daughter was quieter. My wife said: 'I will be with you every step of the way.' I couldn't have asked for anything more, and she was there for me through everything.

'I felt nervous about my first chemotherapy'

The treatment wasn't nearly as bad as I feared. I had imagined it was going to be awful but there were no dramas and it was not painful. I felt great relief that treatment had started and I imagined the various mechanisms by which the different drugs and my immune system would now be attacking the cancer cells.

'I started to recognise the patterns around treatment'

I started to recognise the pattern of how I would feel after treatment. For the first 5 days the steroid prednisolone helped, but by days 6 to 7 the effects of that drug had worn off and I felt really rubbish and tired.

On day 10 my neutrophil count was at its lowest, so I had to be careful because of the risk of infection. I was almost paranoid about getting an infection because I really didn't want any interruption to my treatment.

By the third week, things were looking up, but I knew that meant the next treatment wasn't far off.

I didn't struggle too much with side effects. I lost my hair after the first round of chemotherapy, and had some mouth ulcers and a couple of eye infections. By the third round, I was still managing to ride my bike and go for walks, but after the third or fourth treatment, I noticed my muscles were feeling weaker and I felt much more tired.

'It's strange how cancer puts you on high alert'

Suddenly I was on high alert about things being said or about minor twinges. My throat felt bad on one occasion and I started to think it was spreading, and that the treatment wasn't working. It was only a mouth ulcer!

Ten days after the fourth cycle of chemotherapy I was given a CT scan, so that the team could decide whether to continue with the treatment plan or whether they would need to consider changing it if it wasn't working. This was the first measurement and an important moment. Because I had a lump behind my sternum bone, I couldn't see or feel it, so I couldn't judge whether the lump was going down. But after the first round of chemotherapy, my cough vanished, which I took as a good sign.

The scan showed I was responding well to treatment; the tumour had reduced by more than 50% and had not spread. The plan was therefore to carry on with the chemotherapy, followed by radiotherapy.

'On to radiotherapy, which took its toll'

Because the tumour had reduced so much and was now relatively small, they could target it with radiotherapy, with a total of 30 grays planned. At first I couldn't tell that anything was happening, but by the eighth or ninth session I noticed a few things. I felt very tired and my throat was getting tight. I was also starting to get cramps in my calves, which was really unpleasant. The radiotherapy was taking its toll and I was relieved when it finished.

By mid-March I started to focus on getting fitter again. I knew I needed to build up my muscles, especially in my legs, but didn't want to overdo it. I was shocked at how much slower I was than I had been before treatment.

At the end of April 2017, I had a 3 month post-treatment scan and the results were excellent, I was in complete remission.

'How bad can a bad day get?'

I think my perspective in life has changed. I used to take things very much more seriously, but a cancer diagnosis puts things into perspective. I feel rather humble and very fortunate. I went back to thank my GP for referring me for a chest X-ray and he told me I had been a good patient because I had followed his advice and had come back promptly when the antacid didn't work. It really can pay to listen to your doctor!

Neil

CLINICAL TRIALS UPDATE

The International Conference on Malignant Lymphoma (ICML) took place in Lugano, Switzerland, in June. We caught up with some of the lymphoma experts who attended to find out the latest news in lymphoma research.

The conference provided lots of new insights into the biology of lymphoma, laboratory markers of particular types of lymphoma, and early data on potential new treatments. These are promising for the future of lymphoma research and treatment.

Diffuse large B-cell lymphoma (DLBCL)

The latest research into DLBCL suggests that the type of cell the lymphoma develops from – germinal centre B-cells (GCB) or activated B-cells (ABC) – does **not** make a difference to how well the lymphoma responds to treatment, when new agents are given in combination with conventional chemotherapy. Other markers are needed to predict who will respond well to standard treatment and who might need more intensive treatment.

These might include a measure called 'total metabolic tumour volume' or TMTV, assessed by PET scan. A recent study found that TMTV was an effective indicator for predicting outcomes for people with DLBCL. In future, it could be used with other markers, such as levels of tumour DNA in the blood (circulating tumour DNA or ctDNA), to determine the best treatment for each person with DLBCL. However, at present, there isn't a standardised way of measuring TMTV or ctDNA.

Studies are looking at markers to predict people with DLBCL who will respond well, and those that might need more intensive treatment.

In addition, much more work is needed to make sure the results of these new markers are available in a timeframe that can influence patient care. Long waits for these tests can also lead to delays in treatment.

Other measures that might help predict how well DLBCL responds to treatment might include gene expression profiling, which can be used to identify 'molecular high-grade' DLBCL – a subtype of DLBCL that might need more aggressive treatment. Gene expression profiling involves a specialised laboratory test that is not routinely available at present.

A first-in-human trial of an antibody–toxin conjugate called 'loncastuximab tesirine' showed encouraging efficacy in people with relapsed or refractory DLBCL, particularly in older people or people with transformed lymphoma or primary refractory lymphoma.

A new antibody treatment called 'tafasitamab', which targets a protein called CD19 on B cells, was studied in the **L-MIND trial**. Tafasitamab had promising efficacy when combined with lenalidomide in people with relapsed or refractory DLBCL. It has been submitted to the European Medicines Agency (EMA) for consideration for licensing.

Several studies looked at adapting traditional rituximab plus chemotherapy treatment by adding other agents or modifying treatment duration.

- A trial called **SMART Start** looked at adding two cycles of targeted treatment up-front before starting standard chemo-immunotherapy. The results are promising and are being studied further.
- The **CAVALLI study** added venetoclax to R-CHOP in people with DLBCL that makes a type of protein called BCL-2. Results were promising.
- **The HOVON study** investigated rituximab maintenance treatment after R-CHOP to reduce the risk of relapse. This is standard practice in some other lymphomas. However, it was found to have no benefit for people with DLBCL.

Mantle cell lymphoma

There were several interesting studies involving people with mantle cell lymphoma reported in the conference.

A US trial showed that ibrutinib plus rituximab was a safe and effective alternative to chemotherapy in elderly people with mantle cell lymphoma who had not been treated before. This is being studied further in the **ENRICH trial** being conducted in the UK.

Two studies found that zanubrutinib (a cell signal blocker that targets a protein called BTK) is highly active and well tolerated in people with mantle cell lymphoma. Response rates seem to be higher in Chinese people, but scientists are not yet sure why this is.

The **LYMA-101 trial** found that treatment with obinutuzumab (an antibody therapy) plus DHAP chemotherapy followed by a stem cell transplant resulted in an 'unprecedented' proportion of people achieving minimal residual disease negativity or MRD negativity. This means that lymphoma cells could not be detected using genetic analysis of bone marrow or blood samples.

MRD negativity is linked to better outcomes in MCL. Longer follow-up is needed to see if these responses are durable.

CNS lymphoma

Stem cell transplants have become standard treatment for younger people with CNS lymphoma but they are less often used in older people. The **MARiTA trial** showed that age-adapted induction therapy (initial chemotherapy based on the age of the person being treated) followed by high-dose chemotherapy and a self (autologous) stem cell transplant was safe and effective for fit older people (over 65) with primary CNS lymphoma.

Treatment for CNS lymphoma poses the challenge that standard treatments do not cross the blood – brain barrier.

R-CHOP, a standard treatment for many high-grade lymphomas, is not effective in CNS lymphoma because the drugs are not able to cross the blood–brain barrier (a layer of cells that separates the blood from the central nervous system, stopping harmful chemicals reaching the brain). In the **INGRID trial,** people with relapsed or refractory CNS lymphoma first had treatment with a genetically-engineered protein to disrupt the blood–brain barrier. They then had six cycles of R-CHOP. Initial results were promising.

A French study found that temozolomide, an oral chemotherapy drug that can cross the blood–brain barrier, was effective and well tolerated in people with relapsed or refractory primary intraocular lymphoma (a very rare CNS lymphoma affecting the eyes). It represents a cost-effective treatment option.

For people with secondary CNS lymphoma (lymphoma that started elsewhere and spread to the CNS), international data suggests that intensive chemo-immunotherapy followed by an autologous stem cell transplant produces the most favourable outcomes.

Follicular lymphoma

Interesting studies in follicular lymphoma focused on new treatments, maintenance therapy, and predictors of long-term treatment outcomes.

A new drug called HU5F9-G4 targets the CD47 protein, found on many cancer cells. The protein acts as a 'don't eat me' signal to cells of the inate immune system, allowing the cancer cells to hide from the immune system. Initial results from an early trial found that HU5F9-G4 combined with rituximab was well tolerated and produced rapid and durable responses in people with relapsed or refractory follicular lymphoma. It is an interesting potential new treatment option that is being studied further.

A new oral drug called tazemetostat blocks a protein called EZH2 that regulates how germinal-centre B cells mature. Around 1 in 5 people with follicular lymphoma have mutations in the *EZH2* gene that increase the activity of the EZH2 protein. This might be linked to the development of the lymphoma.

Tazemetostat was effective and well tolerated in people with relapsed and refractory follicular lymphoma. It produced particularly high response rates in people who had a mutation in the *EZH2* gene.

The FOLL12 study showed that omitting rituximab maintenance therapy in people who achieved a complete response to initial treatment for follicular lymphoma resulted in lower progression-free survival but no difference in overall survival. This suggests that more people relapsed if they did not have rituximab maintenance therapy, but they were successfully retreated. The role of maintenance therapy for follicular lymphoma is being studied further in an ongoing study called **PETReA**.

For many lymphomas, a measure called POD24 (progression of disease within 24 months of treatment) can help predict long-term outcomes. A study presented at ICML showed that in people with follicular lymphoma who had had a PET scan at diagnosis, the POD24 measure was less useful at predicting long-term outcomes. Scientists think this is because a baseline PET scan may be able to detect early transformation to DLBCL. This means that the people who go on to be treated for follicular lymphoma, rather than DLBCL, are less likely to have undiagnosed transformation and have better outcomes if they relapse.

Interesting studies in follicular lymphoma focus on new treatments, maintenance therapy and predictors of long-term treatment outcomes.

Chronic lymphocytic leukaemia/small lymphocytic lymphoma (CLL/SLL)

As we reported in the last

Search for clinical trials at lymphoma-action.org.uk/TrialsLink

issue of *Lymphoma Matters*, treatment pathways in CLL/SLL are evolving rapidly.

The **RESONATE 2 study** presented excellent long-term data supporting the use of ibrutinib as first-line therapy. This is already licensed in the UK but it is only available on the NHS for people who have a specific genetic mutation in their CLL cells called '17p deletion'.

Also in previously untreated CLL, fixed-duration venetoclax and obinituzumab is safe and effective in people who have other medical conditions, including older people. It provided superior outcomes to chlorambucil and obinutuzumab. Venetoclax combined with ibrutinib was also shown to be an effective oral treatment option for high-risk and older people with CLL.

Other low-grade non-Hodgkin lymphomas

The **IELSG46 study** identified four different 'molecular' subtypes of splenic marginal zone lymphoma with different genetic profiles. In the future, this information might be used to guide treatment choices.

As with some other types of lymphoma, POD24 was found to be a useful predictor of long-term outcomes in extranodal marginal zone lymphoma.

Preliminary results from the **UNITY-NHL trial** showed that umbralisib, a PI3Kδ inhibitor, was active and well tolerated in people with relapsed or refractory marginal zone lymphoma. Response to treatment seemed to be durable.

Early analysis of data from the **MAGNIFY trial** showed that a combination of lenalidomide (also known as Revlimid®) and rituximab (R^2) was safe and effective in people with relapsed or refractory marginal zone lymphoma.

Long-term data from a study of ibrutinib in relapsed or refractory Waldenström's macroglobulinaemia (WM) confirmed long-lasting responses to treatment. People with a mutation in the *MYD88* gene (present in over 95% of people with WM) but no mutation in the *CXCR4* gene (present in 30% to 40% of people with WM) had the most favourable outcomes.

A small study also found that ibrutinib produced durable treatment responses in people with Bing-Neel syndrome, a rare complication of WM affecting the brain and spinal cord.

Hodgkin lymphoma

A study presented at ICML looked into long-term outcomes of early-stage nodular lymphocyte predominant Hodgkin lymphoma (NLPHL), an uncommon type of Hodgkin lymphoma. The study found that outcomes for early-stage NLPHL were excellent regardless of what treatment people had, although regimens containing radiotherapy produced the best results. There did not seem to be any benefit to having 'combined modality treatment' (radiotherapy plus chemotherapy/immunotherapy) over radiotherapy alone.

Another study looked at whether it's necessary to give radiotherapy to people who have a large residual mass after ABVD treatment for advanced Hodgkin lymphoma. The study found that people with a large residual mass who had a negative PET scan after two cycles of treatment and again at the end of treatment had similar outcomes whether or not they had been treated with radiotherapy. The authors concluded that radiotherapy can be safely omitted in these people, which could reduce the risk

Stock photo

of developing late effects of treatment.

Similarly, people with a fluorodexyglucose (FDG) PET-positive mass at the end of first-line treatment for Hodgkin lymphoma may not need immediate further treatment but can be closely followed up with a further PET scan. A small study showed that almost half of these people became PET-negative after 2 to 3 months. Those who remained PET-positive went on to have a biopsy and received treatment only if residual lymphoma was confirmed. Outcomes were similar to those in people who were treated immediately. This suggests that not treating residual PET-positive Hodgkin lymphoma immediately may avoid unnecessary treatment in some people.

Looking at potential future treatments, two new therapies presented interesting data.

An antibody–toxin conjugate called 'camidanlumab tesirine' showed encouraging efficacy in a phase 1 study in relapsed or refractory Hodgkin lymphoma but caused serious side effects in some people. It is entering a phase 2 study.

Read about T-cell lymphoma trials and studies at lymphoma-action.org.uk/News

A CAR T-cell therapy targeting the CD30 protein is in early phase development.

With thanks to Dr Andy Davies, Senior Lecturer in Medical Oncology, University of Southampton for reviewing this summary.

Lymphoma Action Support Groups

Aylesbury
Bangor
Bath
Bolton
Brighouse
Cambridge
Canterbury
Cardiff
Cheltenham
Chester le Street
Colne
Darlington
Frodsham
Glasgow
Guildford
NEW Harrogate
Isle of Man
Kendal
Lancaster
Leeds
London (North East)
London (North West)
Macclesfield
Manchester
Mold
Nantwich
Norwich
Peterborough
Plymouth
Poole
Portsmouth
Preston
Reading
Southampton
Southport & Ormskirk
St Helens
Teesside
Truro
Warwickshire
Whitehaven
Wigan
Wirral

Lymphoma Action Closed Facebook Support Groups:
North West
South West
Yorkshire & North East

For more information call 0808 808 5555, email information@lymphoma-action.org.uk or visit our website at **lymphoma-action.org.uk/SupportGroups**.

ask the expert

My treatment has finished, why am I feeling so anxious?

Having a cancer diagnosis is a highly significant moment in your life, so it is normal for you to feel scared and stressed. When treatment is finished people expect you (and maybe you expect you) to be getting on with your life.

It can be helpful to think about it this way: imagine you are a young gazelle with not a care in the world. Then a lion comes along out of the blue and eats your best friend. From now on, you are going to be more vigilant. You are not just looking out for lions, but anything yellow will be worrying as will the movement of grass, and even the time of day that the incident happened could be a trigger for anxiety. This vigilance is natural. On the most basic level, it enables you to stay alive and avoid the lion coming to get you. This natural reaction (known as 'fight or flight') is really helpful in short bursts, making the body react more rapidly. While short bursts of anxiety can be manageable, even helpful to get things done, too much can be exhausting, overwhelming and debilitating.

Why does this flare up after treatment? During treatment, many people manage well. You will have had a clear sense of purpose – an aim (getting through treatment) and a plan of action (how you were going to get there, for example counting down chemotherapy sessions). However, when treatment ends, that structure drops away – you are no longer fighting, no longer have a routine and set of goals in the same way. There is now a loss of an obvious focus. You have also lost the regular support from your healthcare team; reassuring medical

surveillance and the comfort of 'something being done'. On top of all that, you may have lost some of your social support, as people around you get back to life as it was before, and assume you will too.

So don't be surprised if, at a time when you are expecting to feel happy and relieved, you actually feel worse. This over-awareness of danger is called 'hypervigilance'. Essentially, with a new, heightened sense of mortality, you're looking out for lions (or early signs of lions). Except that, of course, it's cancer, or early signs of it. For example you'll notice with a new alarm any aches and pains in your body.

In the particular case of people with a lymphoma experience, this hyper-vigilance can be tricky, because some people did not have symptoms, and their lymphoma was picked up by chance. In this case, there is the added worry of not knowing what they are looking for.

Pretty much without exception, the people I see never resume the old 'normal' again. They can never 'un-have-had cancer'. But here's the good news.

The new normal can be better. It can bring a better perspective on what matters, and what doesn't; a better appreciation for the richness of life...'life in HD'. And having that residual anxiety, that sense of 'yes it can happen to me', actually spurs people on. Life's not forever. Now where do I go from here?

With thanks to Dr Dominic Bray, Consultant Clinical Psychologist, Lancashire Care NHS Trust for answering this question.

Should I have a flu jab?

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

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

You need to be vaccinated every year as each year's vaccine is developed based on the virus strains experts think most likely to be around in the coming year. If you are attending hospital regularly for treatment, you may be able to have the flu jab there; otherwise ask your local GP surgery. The flu vaccine does not contain live virus, so you cannot catch flu from having the jab.

Important advice:

- Aim to have the flu vaccination before you commence treatment.
- If on treatment, ask your medical team about the best time to have the vaccination.
- If you have had a transplant, you should receive the flu vaccination 6 months post-transplant and annually thereafter.
- Some children have the nasal spray flu vaccine. This is a live vaccine so you should avoid children who have had it for 2 weeks following their vaccination if your immune system is weakened.

People who are in close contact with you should also have the flu jab.

With thanks to Dr Cathy Burton, Consultant Haematologist at Leeds Teaching Hospitals for answering this question.

Blood Cancer Awareness Month 2019

Thank you to everyone who made September 2019 the most successful Blood Cancer Awareness Month ever for Lymphoma Action.

Over the month, 47 awareness events and 128 fundraising activities were held. We were really touched by all the wonderful stories of how people got involved, and wanted to share just a few of them here.

• Polly (pictured) sold her lavender bags and raised £150. Her dad is currently receiving treatment for Hodgkin lymphoma so she and her brother, Otis, wanted to help raise awareness.

• Kyran travelled 27 miles on his tricycle with his grandma because Kyran's dad was diagnosed with a rare form of Hodgkin lymphoma in May this year.

• Julie held a charity Glowfit exercise class on the 20th September at the Armoury in Flint, North Wales.

• Rebecca raised awareness with a walk and coffee morning.

• Julia is a Support Group Volunteer for Wirral and has been busy organising a coffee morning at The Viking in West Kirby with a celebrity guest for the event – TV chef Simon Rimmer.

• Sue in Teeside encouraged local nursery schools to hold 27 bunny leaps for lymphoma.

• Expeditors UK held coffee mornings in their branches in Bristol, Castle Donnington and Birmingham.

Our wonderful supporters manned 12 stalls in lots of different locations including hospitals, pubs, gyms and chemists.

Thank you to everyone who took part! You can continue with your 27 in 27 fundraising throughout October if you haven't quite finished yet.

Treat someone special to the perfect gift this Christmas with a Forever Flower.

Forever Flowers

A Christmas gift with true meaning

Every Flower you buy will help make sure we can continue to provide support for people affected by lymphoma.

A Forever Flower will make a unique and meaningful Christmas gift. Each flower is hand crafted by award winning sculptor Paul Cox and his team of artists. The flower comes with a beautiful Christmas gift card for you to write your personal message, either in memory or in celebration.

A single flower costs £15, plus £2.50 postage and packaging. Each flower is 35cm in length and 7cm in diameter made from solid steel. The stem is bronze and the petals are purple. Due to the technique used the petal colour does vary and has a rough, mottled effect.

Add a sprinkle of magic to Christmas with a Forever Flower.

You can order your flower online at lymphoma-action.org.uk/ForeverFlowers or call us on 01296 619400.

Our amazing volunteers

Volunteering is at the heart of Lymphoma Action. Over the past 18 months we've invested in developing a volunteering programme and have recently launched our 3 year Volunteering Strategy at lymphoma-action.org.uk/Volunteering

We are truly grateful for the time, passion, skills and commitment volunteers give in helping people affected by lymphoma. We are very fortunate to have volunteers with diverse experiences and a wealth of skills and expertise.

Did you know?

All our volunteers make an impact on people affected by lymphoma. So far this year volunteers have given 2,464 hours of their time across the UK.

The majority of our local support groups are organised and facilitated by volunteers.

We've recently launched a new Support Group Organisers' guide to provide a clear and supportive framework.

Join our community of volunteers

Whatever your reason, by volunteering for Lymphoma Action you will make a real impact on people's lives. Take a look at our website for ways you can get involved. If you don't see something for you, get in touch and we'll discuss other opportunities based on your skills and interests.

- lymphoma-action.org.uk/Volunteering
- volunteering@lymphoma-action.org.uk
- 01296 619424

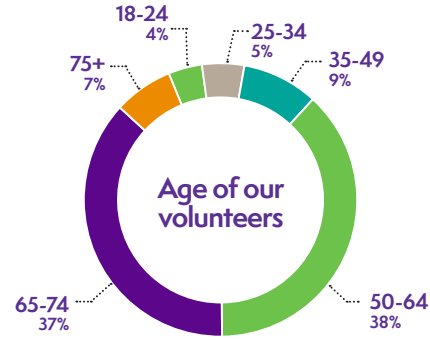
> I volunteer at Lymphoma Action to support my community. Volunteering has helped me gain and develop my skills, which will greatly benefit my future.
>
> *Office Volunteer (Ravi)*

> By being a Support Group Organiser I find my own stress levels decrease. I gain a much better perspective on my own situation when I meet people who have been living with blood cancer for 18+ years.
>
> *Support Group Organiser (Julia)*

> I am interested in using the experience and skills I have gained in my previous employment to help people affected by lymphoma. I also see it as a way of becoming more involved in my local community.
>
> *Office Projects Volunteer (Brian)*

> I had never heard of lymphoma before being diagnosed myself, so I wanted to raise awareness of this common cancer in young people. I also really enjoy being part of a team.
>
> *Young Volunteer Ambassador (Raveen)*

Volunteer Survey 2019

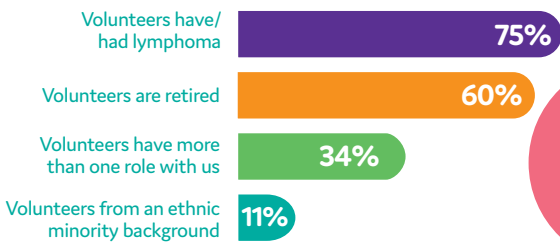


Following our first Volunteer Experience Survey in 2018, we ran the survey again in 2019 to gain feedback from our volunteers. This will inform our next steps.

We have since launched our first Volunteering Strategy which confirms the direction of our work and where we will focus our energy and resources over the next 3 years.

87% are satisfied or extremely satisfied with their volunteer experience

About our volunteers



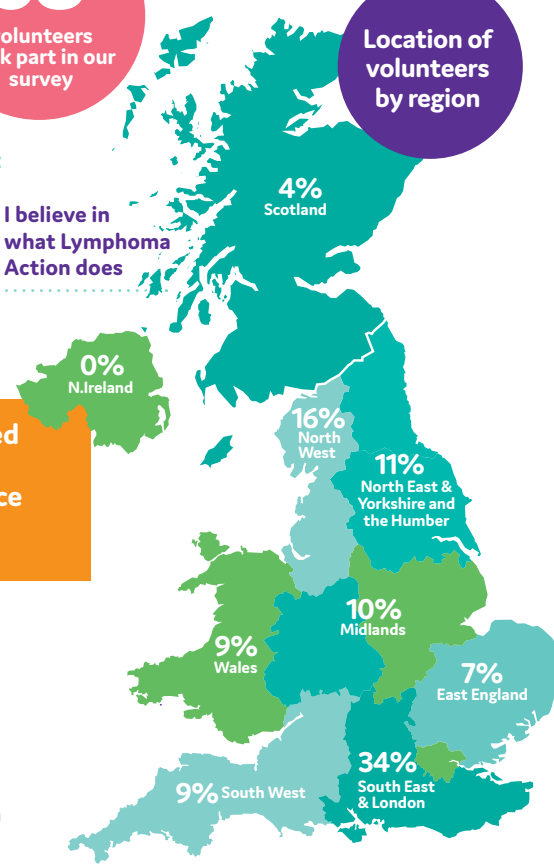
68 volunteers took part in our survey

Top three current reasons for volunteering:

1. My connection to lymphoma
2. I want to make a difference
3. I believe in what Lymphoma Action does

Top three things volunteers have gained over the past year:

- Gained a sense of purpose
- Met new people and made friends
- Developed skills and experience



As a volunteer:

- **87%** have a better understanding of lymphoma
- **72%** feel supported in their role(s)
- **66%** say volunteering has improved their own wellbeing
- **52%** have been given opportunities to connect with other volunteers
- **40%** have got involved in other opportunities with Lymphoma Action since volunteering eg attend events, shared their story

Lymphoma Focus Day

Saturday 16 May 2020

etc.venues Manchester, 11 Portland Street, Manchester M1 3HU

Join our Lymphoma Focus Day (national conference)

Whether you're newly diagnosed, on active monitoring, having treatment, finished treatment or are a family member, friend or carer – this is the event for you.

Hear from expert speakers and meet others who 'get it' in a warm and friendly environment.

Topics

Types of lymphoma
Looking after yourself
Emotional and practical toolkits
Diet and nutrition
New and future treatments

Tickets £30. Find out more and book your place.

01296 619412
conferences@lymphoma-action.org.uk
www.lymphoma-action.org.uk/FocusDay

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