

lymphoma matters

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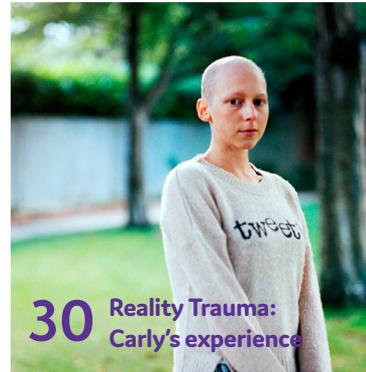
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Lymphoma Action is the UK's only charity dedicated to lymphoma, the fifth most common cancer in the UK, and the most common among young people aged 15 to 24. We've been providing in-depth, expert information and a wide range of support for over 30 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 are those of the contributors. Lymphoma Action does not necessarily agree with or endorse their comments.

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Cover: Carly, who shares her story on page 30.

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Ropinder Gill
Chief Executive

It is more important than ever to have your annual flu jab. Find out more on page 12.



We hope you like this edition of *Lymphoma Matters*. You can sign up to regularly receive our magazine at www.lymphoma-action.org.uk/Sign-Up

Finding new ways

I hope this edition of *Lymphoma Matters* finds you safe and well and that we have been able to provide you with the support you might have needed over the last few challenging months.

You may have noticed that our support groups are now virtual, our conferences have become webinars and the COVID section on our website is updated daily: to name but a few changes we've made in response to the COVID-19 pandemic.

We've been reflecting on what these changes mean for people affected by lymphoma and how we can best provide services in the future. Our new 'Insights Panel', a diverse group of people affected by lymphoma, will be invited to give feedback and insights into what we are doing to help us focus on the impact of our work and ensure that our activities are exactly what are needed. We are delighted to welcome so many new people to our lymphoma community, who have joined our online support groups, our Facebook group and ordered our 'Distance Aware' badges. And we saw a new international audience of healthcare professionals sign up to our online educational events.

The National Lottery were impressed by our work during the pandemic and awarded us a fantastic £100k grant. This will help plug some of our losses this year, for which we are enormously grateful. Our income has also been impacted by other developments that have affected our services: we heard the disappointing but understandable news that the London Marathon wouldn't run as a physical event this year. For us, this event alone would normally contribute £100k through sponsorship.

In order to safeguard services we have taken steps to reduce our costs, although we predict our income levels will not reach those achieved in 2019 until 2023. However, we look to the future with optimism and determination, and hope that the generosity of our supporters will help us through these difficult times. So please do support us if you can.

Ropinder Gill
Chief Executive

Lymphoma Action welcomes new Trustee

We are delighted to announce that James Cray has joined us as a Trustee. James brings over 20 years of HR expertise and is currently Regional Vice President for a large corporate company.

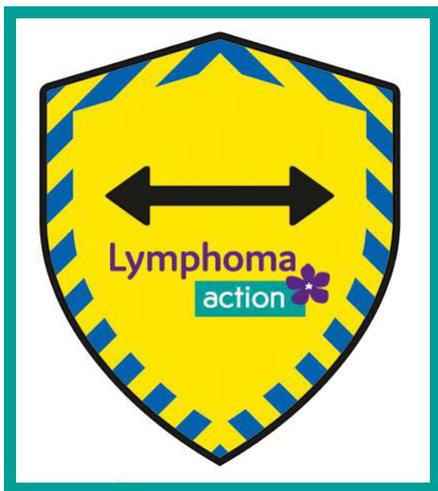


In 2010, James was diagnosed with peripheral T-cell lymphoma, and experienced a recurrence of the condition in 2015. His treatment over the past decade has included chemotherapy and two stem cell transplants.

James understands first-hand the impact that a lymphoma diagnosis can have on people affected by the condition and their loved ones, and commented:

'I'm really excited about the opportunity to give something back to the lymphoma community for all the incredible care, treatment and support I have received. I look forward to helping the organisation to support those affected by lymphoma, and who may be going through an experience similar to my own.'

There's still time to order your Distance Aware badge



We were one of the first charities in the UK to produce a Distance Aware badge to support people who may have concerns around staying safe when outside their homes.

The design was developed by NHS Wales as a means to politely remind others to maintain respectful social distancing where possible.

To order a free Distance Aware pack, which includes two badges, go to www.lymphoma-action.org.uk/Distance-aware-badge

Working in collaboration

Over the last seven months, we have worked more closely than ever with other charities, patient support organisations and health professionals. By doing this we can achieve so much more.

Here are just some examples of where collaboration enhances what we are doing:

- From the beginning of the UK lockdown, the 25 cancer charities that make up One Cancer Voice have worked together to answer questions about COVID-19. This group developed a 12-point plan for the restoration, recovery and transformation of cancer services. Collectively we continue to lobby the Government to ensure cancer services are not only restored to previous levels, but also transformed to deliver significant improvements in survival rates and patient care.
- Our Medical Advisory Panel of clinicians, nurses and other experts in lymphoma, are crucial to our understanding of what is happening at the front line. It is invaluable in helping us communicate the changes that are being made to ensure everyone's safety.



- We are working with Leukaemia Care to deliver a range of webinars, and were delighted to work alongside other patient organisations who represent some of the rarer lymphomas, such as WMUK to provide a webinar on Waldenström's macroglobulinaemia.

To check out all our recent videos go to: www.lymphoma-action.org.uk/COVID19

By working together we can have a greater impact and reach more people.

Lymphoma registry

Nottingham University Hospitals (NUH) have set up a registry that will collect data on all newly diagnosed lymphoma patients treated at NUH and other hospitals in the Midlands. Patients often live with lymphoma for many years, so it is hoped that registries, like that being compiled in Nottingham, will highlight any problems people may have in the future. We look forward to reporting more on this project in future issues.

A photograph of a man and a woman smiling. The man on the left is bald, wearing glasses and a dark jacket over a striped shirt. The woman on the right has blonde hair and is wearing a white top. They are outdoors, with a building and trees visible in the background.

Mark's story

Mark shares his experience of CAR T-cell therapy.

My lymphoma story began in 2018. I was 62, married to Diane and had three grown-up children. We have a close relationship with our children, who have been a great support over the last 19 months.

I was working as a specialist endodontist in dental practice and teaching the subject (root filling teeth) to post-graduate students, working full time and finding life both busy and rewarding.

I had taken up running 5 or 6 years previously and found it a good stress reliever and great fun. Di and I are keen to remain fit and over previous holidays we had walked up the highest peaks in Wales and Scotland – Snowdon and Ben Nevis. To celebrate Diane reducing her working hours

(she is a hygiene therapist working in practice and teaching too) we decided to climb the highest mountain in England, Scafell Pike in the Lake District. Although we made it to the top, this success was followed later that day with an un-scheduled, unprotected night out on this mountain due to a navigational mishap! It was a painful experience and one we look back on as a 'benchmark' for how challenging things are. More of that later.

I had not visited a doctor since I was a teenager, but was struggling with abdominal pain. In December 2018 Di, who instinctively knew something was wrong, overruled my tendency to allow 'things to find their own place'.

With hindsight, it is a less than clever attitude, ignoring warning signs! I hadn't even mentioned a swelling I'd noticed above my left clavicle, as it seemed insignificant at the time and unconnected with my 'gut' pain, which was coming intermittently, but at times quite uncomfortably.

In December, my GP arranged for some blood tests to determine the cause of my symptoms. The results showed I was suffering from chronic kidney disease, but this didn't seem to add up as I was feeling too fit to have kidney disease. Further blood tests and an examination, including an ultrasound scan, indicated that my kidneys were causing a problem, but were not the prime cause of my developing illness, which included some altered sensation in my right leg.

Friday 11 January 2019 was a life-changing 'watershed'. It was the last day I worked and I was admitted to hospital urgently for investigation. My usual routine had to stop and I would have to 'let go', allowing events to unfold.

The next two weeks were a venture into the unknown. I had daily blood tests, a lumbar puncture, bilateral nephrostomies (drains put into each kidney to help them function), a full body CT scan, an MRI scan, ECG and heart ultrasound scan and a biopsy taken from an enlarged lymph node just above my left clavicle. An initial diagnosis of non-Hodgkin B-cell lymphoma was made. I was placed on a high dose of oral steroids to start a breakdown of the tumours.

The diagnosis was refined as diffuse large B-cell non-Hodgkin lymphoma (DLBCL) with underlying follicular lymphoma, which I could have had for years! I was reassured that treatment for DLBCL was given with a 'curative intent', and that it would start straight away with R-CHOP chemotherapy. The first course of chemotherapy was administered as an inpatient to ensure a safe tolerance of the drug regimen and so that they could monitor my kidney function.

After 2 weeks, I was allowed home. Hooray! But, within 72 hours I developed a high temperature and was re-admitted. I was given a course of IV antibiotics and more daily early morning blood tests! Five days later I was relieved to be at home again.

The five remaining scheduled sessions of R-CHOP chemotherapy were given as an outpatient at 3-week intervals and ended in mid-May 2019. There was always the most positive 'banter' with the nursing staff and fellow patients; very much part of the 'therapy'! A PET scan showed an inconclusive response. A further PET scan 3 weeks later showed some improvement, but active disease was still present.

At the end of June 2019, my Consultant explained that they were going to change my chemotherapy regimen to R-ICE. This was planned to involve a further three cycles, this time as an inpatient Monday to Friday at the start of each cycle (again 3-week intervals), then I would have an autologous stem cell transplant, using my own stem cells.

After the second R-ICE cycle, I had a further PET scan. Again, the results were inconclusive and it was determined that further R-ICE and a stem cell transplant would not be therapeutic. Another form of therapy was needed.



Before we knew what was in store

My Consultant spoke to me about the option of CAR T-cell therapy. I wouldn't be able to have this treatment at my usual hospital, so would need to be transferred to a larger centre. She explained that because I came to treatment as a fit individual, I would be a likely candidate. However, I would need to be assessed and 'put forward' for consideration.

'Friday 11 January 2019 was a life-changing 'watershed'. My usual routine had to stop and I would have to 'let go', allowing events to unfold.'

I recalled at the time how I had recently seen news coverage on the television of the first lymphoma patient to have had successful CAR T-cell therapy on the NHS. I hadn't realised at the time that this might be an option for me.

A consultation was arranged which felt like a momentous meeting, and one that would have great significance to my health outlook. I was accompanied again by my wonderfully supportive wife Diane, as I have been to all my appointments.

Those we are closest to have to bear an equally uncomfortable journey of unknowns when we are ill.

I wonder whether their journey is even more difficult than ours as a patient? Theirs is full of the uncertainties we are experiencing; attending, living alongside, wanting to help, but not being able to do more than watch, support and be a 'shoulder to cry on' if necessary. We just have to go with the flow and accept our treatment, as if in the centre of the wheel of activity.

'I felt it was a great privilege that I was to be considered for this new treatment, CAR T-cell therapy. What enormous advances have been made in science; we are standing on the shoulders of giants, aren't we?'

My kidney function was back to normal, which was necessary before CAR T-cell therapy could be entertained. Additionally, I had a further biopsy of a swelling that had appeared just in front of my right ear, plus a further heart scan to measure my baseline cardiac function before treatment.

My T cells were harvested towards the end of October 2019. The apheresis team explained how the cells would be stored, protected and whisked off by courier. They were sent to the USA within 24 hours where the magic of CAR T-cell transformation began.

Pending the T-cell return, I was given a further course of chemotherapy to maintain the status quo, this time orally.

The week before the T-cell return (which is usually after 4 weeks) it is necessary to reduce the body's natural defensive response so a further course of chemo was given. Three days of intravenous chemo as an outpatient were interrupted by a weekend off followed by admission to the isolation ward at the hospital on 9 December 2019.

Later that day the CAR T-cells were delivered back to me after 5 weeks, having been genetically modified on the other side of the Atlantic! They are stored at -70°C in a polystyrene container within liquid nitrogen. Thick insulating protective gloves are necessary when withdrawing the frame containing the bag of cells.

Mark in the apheresis unit where his T-cells were harvested



A water bath brings the bag of cells to body temperature. Then they are delivered via a central line and a drip. The whole procedure took around 8 minutes from thawing to completion of delivery. The procedure was very dramatic and swift, with a 'degree of high drama' and then there was a sense of anti-climax once it was over!

For the next 6 days I acclimatised to isolation in a bespoke and very well-equipped room with strict rules to avoid infection.

The first 6 days left me thinking I was experiencing a placebo effect! I felt no different. Daily questions are asked as a routine post CAR T-cell therapy to check for neurological complications, such as what day of the week it is, counting backwards from 100 in tens, plus

'I'm not seeking 'recovery', as I don't expect to go back to where I started. I view my experience of CAR T-cell therapy as a form of restoration and 'renaissance' to life.'

writing a short sentence. At this time, it seemed unnecessary.

However, I developed a high temperature on day six, and I felt unwell and slowly my energies seemed to drain away day-by-day. The tests are designed to check for neurological changes in co-ordination and cognition. My hand tended to shake as days went by, I noticed how my fine motor control had diminished. Interestingly, as well at this time, a previous small swelling on my right cheek increased in size over a few days. It signalled a need for further scans and tests which were carried out. The swelling disappeared as quickly

as it had appeared, but more completely. The CAR T-cells were evidently at work!

This response is expected and is an effect called cytokine release syndrome (CRS), where the CAR T-cell treatment causes an immune reaction in the body, a graft-versus-host type of response. It can be very severe, requiring admission to the intensive care unit. Fortunately, I avoided this! However, I did feel very unwell, at times.

Every few days additional blood was taken to check for infection. There were times when I felt as though my very 'life force' was fading away.

Removing the CAR T-cells from their liquid nitrogen container



I was in hospital from 9 December 2019 until 3 January 2020. I have, and continue to have, routine checks at weekly or bi-weekly intervals. The last three PET scans have shown that the lymphoma tissue has been eradicated and I am in full remission!

I have been home for 9 months now and the coronavirus is firmly part of our lives. Self-isolation is a necessary way of life having a less than fully functional immune system. I know I will never be the same person after this experience; I don't use the term 'recover', but wish to grow and move on. I now want to embrace the new life I have. I have to go into hospital for regular blood tests and some treatment, currently on a weekly basis. I also currently take antiviral, anti-fungal and antibiotic medicines to help give additional protection while my bone marrow and body is returning to normal, but I have found all these things very do-able.

I have a huge sense of gratitude for everyone involved in my care. My wife and three adult children have been fantastic – they have suffered because they have felt so helpless at times. And the care I have received from the healthcare teams within the NHS at both hospitals I've been treated in has been outstanding; I am enormously grateful to them all.

Exercise has been a big part of my return to health and I am back to running on a daily basis, which is bringing so many benefits both physically and emotionally.



Would I swap places with anyone? No, not at all, despite the many hospital visits, stays and procedures, it has been a valuable insight into life, which – dare I admit it – we take for granted much of the time. Is the journey to, and through CAR T-cell therapy as scary and as painful as an unscheduled night out on a snow-covered mountain like Scafell Pike? No, not for me. What CAR T-cell therapy has given is hope, opportunity and life, and it will be a continuing 'journey' to live life's potential, and to live it to the full!

Read Mark's full story at www.lymphoma-action.org.uk/Mark

What is CAR T-cell therapy?

T cells (T lymphocytes) are cells of your immune system. They help your body fight infections and disease, including cancer. Sometimes, abnormal cells can't be detected by your immune system and build up into a cancer. In CAR T-cell therapy, your own T cells are collected and genetically modified to recognise and kill lymphoma cells.

The genetic modification produces chimeric antigen receptors (CARs) on the surface of the T cells. These antigen receptors recognise the proteins (antigens) on the surface of the cancer cells. The modified (CAR) T-cells are able to attach to and destroy the cancer cells.

CAR T-cell therapy can cause serious side effects. The treatment can only be given in hospitals with the facilities to treat these side effects effectively.

Live your Life workshops go virtual



Our award-winning Live your Life workshops are now available virtually.

The first workshops took place in September. They offer interactive online events that you can access via Zoom.

These one-day virtual workshops will help you take control of living with and beyond lymphoma, whether you've recently finished treatment or are on active monitoring (watch and wait). They are led by people with personal experience of lymphoma, and topics include:

- What is lymphoma?
- Signs of relapse
- Coping with the emotional aspects
- Maintaining a healthy, active lifestyle
- Diet and nutrition.

Live your Life virtual events are free and you're welcome to invite someone to attend with you. Find out more, or register for a Live your Life workshop at:

www.lymphoma-action.org.uk/LYL

Lymphoma Outloud launches with Dr Sarah Jarvis interview

We were delighted to launch our new series of podcasts with a conversation with Dr Sarah Jarvis, who you might know from *The One Show* and the *Jeremy Vine* programme.

Dr Jarvis spoke about the complexity of lymphoma and the importance of making an accurate diagnosis. In conversation she talked about the role of the GP, not just in referring people who have symptoms of lymphoma, but also for those living with a lymphoma diagnosis. She emphasised that your GP surgery may be the best place for flu jabs, health screening and practical advice on such things as benefits and available services.

Although there have been many changes affecting visits to the GP since the COVID-19 outbreak, Dr Jarvis commented that some are proving positive, such as telephone or video consultation, avoiding the need for a visit in-person. Of course – you will still be seen by the doctor in person if you need to.

Dr Jarvis concluded that COVID-19 is not the only illness around, and that people should not hesitate to contact their GP or clinical team if they have any health concerns.

Check out our podcast at www.lymphoma-action.org.uk/SJPodcast



Should I have the 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), or if you are having chemotherapy, steroids or radiotherapy. These can suppress your immune system, making you more vulnerable to flu. People who are in close contact with you should also have the flu jab.

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 injectable flu vaccine does not contain live virus, so you cannot catch flu from having it.

Important advice:

- Aim to have the flu vaccination before you start treatment if possible.
- If on treatment, ask your medical team when it is best to have the vaccination.
- If you have had a transplant, you should receive the flu vaccination 6 months post-treatment and annually thereafter.
- Some children have the nasal 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.

This year will see a more comprehensive flu vaccination programme. Why is this and is it connected to COVID-19?

There is a strategic NHS plan to get more people vaccinated against the flu this winter. The Government have stated that, in addition to the people who normally would be recommended to have the flu vaccine (people who have lymphoma are in this category) the recommendation this year covers extended groups of people.

The free flu vaccine will initially be available to:

- people aged 65 and over
- people who were shielding and members of their household
- people with certain pre-existing medical conditions
- all school year groups up to year 7
- pregnant women.

Once vaccination of the most 'at-risk' groups is well underway, the NHS will decide when to open the programme for people aged 50-64, with further details to be announced. We understand that the NHS will contact people directly, with information about where to go for vaccination.

The aim of vaccinating more people is to reduce the incidence of seasonal flu by creating a high level of immunity in the community. Without this, you are more likely

to contract the flu yourself, and more likely to infect others. With a high level of community vaccination, it is passed on to fewer people.

There are good reasons for wanting to keep the seasonal flu under control, particularly this winter:

- Flu is more serious for the same group of people who are at increased risk from COVID-19 - older people, those with heart or respiratory problems and those who are immunosuppressed.
- According to the NHS website, research shows that you are more likely to be seriously ill if you get flu and COVID-19 at the same time.
- If we have a flu outbreak, it will be an extra burden on the NHS.

We know that both COVID-19 and seasonal flu are more dangerous for those who are older and those with health conditions, so it is hoped that around 90% of this group can be vaccinated against the seasonal flu. There are some who will not be able to be vaccinated, but as long as there are high levels of vaccination in the country, it is expected that the transmission of flu will be reduced.

With thanks to Dr Cathy Burton, Consultant Haematologist at St James's University Hospital, Leeds and Philip Hook, Pharmacist at North Bristol NHS Trust, for answering our questions.

The NHS is still open

In these challenging times of COVID-19, we know that people are concerned about overloading the NHS. However, COVID-19 is not the only health condition, and it is important that you don't ignore symptoms that could be serious. If you have symptoms of lymphoma, are worried your lymphoma has relapsed, or signs of infection, please contact your GP surgery or your clinical team.

Fundraising goes virtual!

Virtual Balloon Race in the Rift Valley – Saturday 14 November



Please join us for this fantastic new fundraising event, one for the whole family to join in!

Fun, educational, interactive and environmentally friendly. Buy a virtual balloon and enter our virtual race on Saturday 14 November. It will be held in the Rift Valley, Kenya and you will be able to track your balloon for 7 days using the virtual balloon race website.

Each balloon is subject to a simulated flight pattern based on the actual weather conditions, such as the wind speed and current temperature. The balloon that travels the furthest in 7 days will win a Christmas hamper!

A balloon costs just £3 and you can buy as many as you like. You can decorate and name your balloon, and you never know, it might help it travel further! We aim to sell 1,622 balloons – one for every person who will be diagnosed in the UK with lymphoma in November.

Don't let this float past you: www.lymphoma-action.org.uk/Virtual-Balloon-Race

Festive Fashion Day – Friday 4 December

Whether you're in the office, at school or on Zoom with family and friends – get involved in Festive Fashion Day. Get your Christmas jumper/dress/tie/socks on, cover with tinsel and hold a competition with a prize for the most festive fashion.

Find out more at www.lymphoma-action.org.uk/festive-fashion-day



Why not get involved?

Virtual Santa Run – Saturday 5 and Sunday 6 December



Be part of something amazing this year and run or walk 5K at your own pace, in your preferred place, with family or friends. Kick off the festive cheer by dressing up in your Christmassy gear and run 5k on the road, on a trail, on a treadmill, at the gym or at home.

Alternatively, take a festive 5K walk and take in your local Christmas lights.

You will help raise much needed funds for Lymphoma Action at the same time as spreading festive cheer and having fun! Registration is £5. All those who register will get a hat and festive mask to wear! We just ask that you raise £50 or more on your virtual Santa Run.

To get your jingle on, register at www.lymphoma-action.org.uk/Virtual-Santa-Run

Christmas shopping online

We're excited to announce...

We can now accept automatic penny donations through Roundups.

What is Roundups?

An app that links to your card and donates pennies as you spend.



Check out our marvellous Christmas cards and don't forget when you are Christmas shopping this year you can also sign up to support people affected by lymphoma at no extra cost while shopping online with:

- Amazon Smile
- Give as you Live
- easyfundraising
- Roundups (see picture).



Cancer-related fatigue

Cancer-related fatigue (CRF) is extreme tiredness that's not proportional to activity and doesn't necessarily go away after rest or sleep. It doesn't feel the same as normal tiredness after working hard or exercising: it's much more troublesome. It affects almost everybody who has cancer at some point in their illness, and it's often listed as the most common symptom in people with blood cancer, including lymphoma.

Fatigue can be difficult to describe. People talk about 'all-encompassing' feelings of 'weakness' and 'exhaustion'. Some people use words like 'debilitating' and being 'drained of energy'.

Why am I experiencing fatigue?

It's not clear exactly why cancer causes fatigue. It's probably a combination of factors, including:

- physical effects of the cancer and cancer treatments
- muscle weakness caused by lower than normal levels of activity
- sleeping difficulties or the emotional impact of having cancer
- eating less because of sickness or poor appetite
- side effects of cancer treatments, such as anaemia or infections

- genetic factors
- some medicines, such as antihistamines, antidepressants, strong painkillers and anti-sickness drugs may also contribute.

How long does cancer-related fatigue last?

Fatigue usually gets better gradually after you finish cancer treatment. The time it takes varies from person-to-person, but it's common for fatigue to last for months after treatment has ended. For some people, it can last a year or more. In a few people, it may persist for several years, although it usually gets less troublesome over time.

If you have fatigue that starts or gets worse months after treatment, tell your medical team.

Is there anything I can do to improve it?

If you are affected by fatigue, tell your medical team. They can offer you advice about what support is available for you.

Medicines to treat fatigue have mixed results and aren't recommended for routine use. However, here are some things you can do to reduce the impact of fatigue on your life:

- Ask your doctor if there are factors that might be making your fatigue worse, such as anaemia, depression or anxiety, pain, dietary issues, medicines or other illnesses. Treating these might improve your fatigue.
- Ask if a referral for physiotherapy, occupational therapy or cognitive behavior therapy (CBT, or talking therapy) with a professional who specialises in CRF might be appropriate.
- Try distractions such as games, music or reading to help you cope with fatigue. Relaxation and complementary therapies such as yoga and mindfulness might help.
- Have a regular sleep pattern.

The three Ps: Plan, Prioritise and Pace

Some days you may have more energy than others. If you don't have enough energy to do everything you'd like to, try to prioritise:

- Work out when in the day you have the most energy and prioritise the most important activities or work to do during this time.
- Plan regular rest breaks but try not to sleep during these rests as this can disrupt your night-time sleeping pattern.
- Delegate tasks to other people where you can; use your energy for the tasks that only you can do or for the ones you enjoy most.
- Try keeping a fatigue diary so you can track your activity levels each day. This might help you spot any triggers to your fatigue and help you plan activities and rest.
- Set yourself realistic and achievable goals; don't be too ambitious.

It is tempting to overdo things as soon as you have some energy, but you risk draining your energy reserves completely and exhausting yourself. This kind of 'boom–bust' cycle can make your fatigue worse.

Exercise and physical activity

Exercise is one of the best things you can do to help fatigue. Being active can improve fatigue, physical health and quality of life in people with lymphoma. There is no particular type of exercise that seems to be better than others for fatigue, and a short walk can be a good starting point. Do what you prefer or ask your medical team for advice on the type of exercise that would be best for you. Try to exercise up to three times a week if you can and increase what you do gradually, depending on how your body is coping. Exercise can make you more tired than you are used to at first, so rest afterwards, but in the long run it can help you feel better.

Diet and nutrition

Eating the right foods to provide enough calories, protein and vitamins is important. Grazing on healthy snacks during the day may help you top up your energy levels.

Explain to people how you feel

If you have fatigue, tell your partner, family and friends how you are feeling. Don't be afraid to ask for help; it is a positive thing you can do to manage your energy levels and people close to you often welcome the chance to do something practical to help.

With thanks to Nikie Catchpool, Consultant Occupational Therapist and Macmillan Professional, Bath Centre for Fatigue Services, for reviewing this article.

Sandra's story

Sandra shares her experience
of having COVID-19



In 2010 I was diagnosed with Waldenström's macroglobulinaemia, a low-grade non-Hodgkin lymphoma.

I had worked for the NHS for 27 years but had noticed I was getting really tired. I put it down to the stress of the job, so decided it was time to leave that role. But the tiredness continued and in addition I started to develop stomach pains. I went to see my GP who referred me for tests. I was fortunate that my diagnosis of Waldenström's macroglobulinaemia (WM) was picked up straightaway.

My father-in-law had had low-grade non-Hodgkin lymphoma and tended to need treatment every 2 years or so. I thought the

same scenario would be the case for me too.

After diagnosis I was put on active monitoring (watch and wait) which lasted for 6 years. In 2016, after developing symptoms, it was decided that I should start chemotherapy and was treated with RCP (rituximab with cyclophosphamide and the steroid prednisolone). Unfortunately the RCP only managed to give me a partial remission until May 2019 and I then started treatment with ibrutinib, which is a targeted drug taken daily as a tablet. I had a really good response to ibrutinib, which was keeping my WM under control.

At the beginning of March I had an overnight trip planned with my sisters. One of them

began to feel cold and achy with a temperature, but at the time this didn't really ring any alarm bells for us as COVID-19 was still very much restricted to people who had been travelling. My sister continued to go downhill and three days later I also had a temperature and felt cold and shivery with aching joints.

After calling the hospital, they suggested I go to A&E. They told me what I had was viral, but when I asked if it could be COVID-19, they said that because I hadn't travelled I did not fit the criteria of people likely to have it.

A week later, as I still had a high temperature and joint pain, I was tested for COVID-19. I clearly remember being told I had tested positive and being

so scared of the implications of having lymphoma too.

I was still really poorly a few days later and was struggling with nausea and vomiting. I couldn't keep any fluids down so got in touch with my clinical team. I was admitted to hospital where I was invited to take part in the RECOVERY trial, which looked at the benefits of dexamethasone (see page 20). I recovered really well and was able to go home.

At home I started to feel breathless after 24 hours, which was really frightening. I was taken back into hospital where I was given oxygen to help. It was really scary and I honestly thought it could only end one way. I had received the shielding letter that had spelled out the dangers if I got COVID-19.

Fortunately, I didn't need to be ventilated but spent 4 weeks in hospital. It was such a hard time, especially as I wasn't allowed any visitors. Aren't we lucky to live in an era of mobile phones? At least we could keep in touch.

When I was diagnosed with COVID-19 I had to stop taking the ibrutinib as it is an immunosuppressant. I then became anaemic and needed a blood transfusion and there was much discussion between the haematology and COVID teams to try and determine whether the problems were caused by the lymphoma or COVID-19.

As my breathing continued to cause me real difficulties and it was hard to get off the oxygen completely, a CT scan was done which showed blood clots in my lung. I needed to use anticoagulants, which I had to inject myself with for 3 months.

I finally came home for Easter weekend, once my breathing had improved.

Unfortunately I still had a temperature after a week of being home, so was admitted back into hospital for a week, while the doctors established that the temperature was most likely caused by the uncontrolled lymphoma.

It was a difficult decision for my lymphoma team to start me back on ibrutinib while I was still on the anticoagulant for the blood clot, but they felt my need for treatment overcame the concerns over any potential bleeding issues.

I consider myself really lucky, especially as I'm not struggling with long term symptoms of COVID-19 as some people are. I was fearful of what would happen when I was diagnosed. I went through so much but am delighted that the lymphoma didn't stop me beating it. Although I am nervous, I am now able to enjoy being outside and going for walks.



And my family? To everyone's surprise my husband didn't get COVID-19 (he has had an antibody test). My sister recovered after about 2 weeks and although she feels guilty having seen me early in March, we couldn't have known what was ahead of us.

My family were a huge support for me while I was ill. I am also immensely grateful to the team who looked after me when I had COVID-19 and also to my haematology team, who have always looked after me so well and got me back on treatment and to my pre-COVID blood levels.

About the RECOVERY trial

Dexamethasone is a corticosteroid used in a wide range of conditions for its anti-inflammatory and immunosuppressant effects. It was tested in hospitalised patients with COVID-19 in the UK nationally in the RECOVERY trial and was found to have benefits for critically ill patients. Preliminary findings indicate that for patients on ventilator treatment, dexamethasone reduces risk of dying by about one-third and for patients requiring oxygen, mortality is cut by about one-fifth.

About ibrutinib

Many newer treatments for lymphoma are targeted drugs, such as ibrutinib. Targeted drugs aim to work on cancerous cells more precisely than treatments like chemotherapy, with fewer effects on healthy cells. Ibrutinib is a targeted drug that blocks the signals B cells (the cells that are abnormal in B-cell lymphomas like WM) need to stay alive and divide. This causes the B cells to die. WM has shown a good response to ibrutinib, with about 9 in 10 people responding to it in a 63 person trial.

Sam's 12 hour cycle challenge

Fundraising in memory

Organising an event in memory of a loved one can be a touching way to honour their life while raising money for charity.

Earlier this year, Sam used his time away from school during the lockdown as an opportunity to train for, and complete, an epic endurance challenge. We spoke to Sam to find out more about his challenge, and his thoughts on fundraising in memory of a loved one.

'On 10 July 2020 I cycled continuously for 12 hours around my local area. I covered 174 miles, only stopping to refill my water bottle (and my pockets with snacks) to raise as much money as possible for Lymphoma Action. I lost my cousin, Ella, in November last year, and she was my motivation for it all. It hit me really badly when she died but I had some really helpful advice from a therapist who told me to live my life in a way that Ella would want me to live it.



I've always been into my cycling, and have always liked the idea of an endurance challenge, so when lockdown came I thought this was the perfect opportunity to do something in aid of Lymphoma Action and Ella.

I wasn't at school so I could get out cycling more, and spent 2 months training and working on my endurance. It was still physically tough to cycle for 12 hours without stopping, but thinking of Ella kept me going, and honouring her was my end goal. She was my finish line.

I had no idea I would end up raising so much money!

The current total is £15,609 including Gift Aid!

My main fundraising tip would be to make sure you get your story out there and spread the word. I set up a JustGiving page and made sure I shared my personal story in the description – I wrote about the challenge and about how Ella was my motivation.

I also created an account on Instagram specifically for the challenge, which people could follow to see all the training I was doing, and see how much this meant to me. In addition, I sent messages to family and friends and they spread the word too.



Thinking of Ella kept me going, and honouring her was my end goal. She was my finish line.

Lymphoma Action helped my family a lot. I was speaking to Ella's husband the other day and he summed it up really well by saying that without the information and support from Lymphoma Action we would have felt a lot more powerless throughout Ella's illness. So I'm really proud to have raised so much money to help Lymphoma Action be there for other families when they need it.'

If you're interested in taking on a fundraising challenge for #TeamLymphoma, or would like any advice on fundraising in memory, we are here to support you! You can get in touch with our Fundraising Team by emailing fundraising@lymphoma-action.org.uk or see our tips online at www.lymphoma-action.org.uk/fundraising-from-home.

Making sure the patient voice is heard at health technology assessments



Lymphoma Action's Director of Operations and External Affairs, Stephen Scowcroft, explains what health technology assessments are and why Lymphoma Action is proud to be a voice for people affected by lymphoma.

What are health technology assessments?

Any new medicine, treatment, medical device, diagnostic technique, vaccine, procedure, or system developed to solve a health problem must go through an evaluation called a health technology assessment (HTA).

An HTA process assesses whether a new treatment is clinically and cost effective. Clinical evidence shows how well the medicine or treatment works. Cost effectiveness shows how well the medicine

or treatment works in relation to how much it costs the NHS – whether it represents value for money. HTAs are conducted by an independent multidisciplinary group to ensure that patients receive the best treatments, and the NHS is getting value for money.

Before any drug can be recommended, it first needs to be approved and licensed by the European Medicines Agency (EMA) for use in Europe (currently including the United Kingdom). This means it has been rigorously assessed to prove that it is safe and effective. An HTA is used to decide whether or

not it should be funded on the NHS. To speed up the process, and make drugs available for patients more rapidly, the EMA and HTA assessment are often carried out at the same time.

Who carries out HTAs?

At the request of the Government's Department of Health and Social Care, HTAs are carried out by the National Institute for Health and Care Excellence (NICE). NICE is independent from the NHS and Government. For a health technology assessment, NICE reviews the clinical and cost effectiveness of new treatments in order

to make recommendations to the NHS in England; often referred to as 'NICE guidance'. Wales and Northern Ireland usually follow NICE guidance. Scotland follows a different process, run by the Scottish Medicines Consortium.

The NHS is legally obliged to fund any medicines and treatments recommended by NICE's technology appraisals programme. When NICE recommends a treatment 'as an option', the NHS must make sure it is available within 3 months (unless otherwise specified) of its date of publication. This means that, if a patient has a disease or condition and the doctor responsible for their care thinks that the drug or technology is the right treatment, it should be available for use, in line with NICE's recommendations.

What stages does an HTA go through?

There are a number of steps involved in an HTA, but broadly they fit into the following key areas:

- scoping
- gathering the evidence
- reviewing the evidence
- final recommendations.

Scoping: At this stage, NICE develops a detailed framework that specifies what the HTA aims to answer. The

scoping document defines: the drug or technology that's being assessed; the disease it's being assessed for; where in the treatment pathway it's expected to fit; and what other treatments it should be compared with. NICE sends the draft scoping document to stakeholders, including medical experts and patient representative groups like Lymphoma Action, for comments. The drug company that produces the technology being assessed also has the opportunity to comment.

Gathering evidence: NICE contacts stakeholders to gather evidence from a wide, multidisciplinary group. Patient carer organisations, NHS organisations and professional organisations are all involved. As a patient carer organisation, our role is to provide information on how the disease being assessed impacts the day-to-day lives of patients and carers, what it's like to have the treatments that are currently available, and the impact that the treatment might have, based on clinical data and patient experiences.

Reviewing the evidence: NICE holds a committee meeting to review evidence from the consultation. Stakeholders – including

patient experts and patient representative groups such as Lymphoma Action – are invited to attend and contribute to these meetings. Members of the public are able to observe the meeting. Draft recommendations are issued for stakeholder and wider public consultation where necessary. This is an 'appraisal consultation document' (ACD).

Final recommendations:

Following stakeholder/wider public consultation on the draft recommendations, or when a consultation is not needed, NICE produces a 'final appraisal document' (FAD) containing its recommendation. Stakeholders have an opportunity to appeal the decision in the FAD before NICE publishes its final decision.

Who is involved in the HTA process?

In England, HTAs involve NICE, clinical stakeholders (medical professionals), patient stakeholders (such as Lymphoma Action), the drug company that makes the new technology and independent health economic group representatives: this is the 'evidence review group' (ERG). NICE appoints the ERG to do an independent economic assessment on their behalf.

Lymphoma Action are invited to represent the patient voice at all HTAs that are related to blood cancer. As specialists in lymphoma, we focus only on lymphoma-specific HTAs. We are made aware of these when we receive a scoping document.

'HTAs can be very technical, and focus on complex scientific and economic data. By representing the patient voice, we make sure that the people involved in the decision-making process keep the patient at the heart of the decision.'

Reading quality of life statistics in a clinical report is very different from hearing about the real impact of lymphoma and its treatment, first-hand.'

Vicki Gregory, Senior Medical Writer at Lymphoma Action

How are Lymphoma Action involved in HTAs?

NICE writes to stakeholders with a set of questions to respond to and a timetable. These assessments can span a long time, and can take up to 18 months (although NICE aims to produce its final recommendations within 3 months of a new drug receiving its licence).

We sometimes contact our Medical Advisory Panel (MAP), a group of health professionals who specialise in the care of people with lymphoma. They help to identify if there are any reasons for us **not** to support an HTA, for example if there is not enough clinical evidence to support the new technology. They also advise on where the technology would fit in current treatment pathways, if approved.

In order to respond to the questions posed by NICE, we aim to involve people who have been treated with the specific drug being assessed, usually as part of a clinical trial. However, this is not always possible. In this case, we involve people with the specific lymphoma type. We usually invite people to come forward on social media. If we are unable to get enough responses, we might ask the MAP to help us find suitable people. We always try to get as wide an input as possible. We send a questionnaire to people who have volunteered to be involved, and then collate all the responses. We use these to prepare a patient organisation response that we submit to NICE.

We are invited to the committee meeting. If possible, we also nominate a patient representative to attend.

This can be a person with lymphoma or the carer of a person with lymphoma.

Only patient organisation stakeholders such as Lymphoma Action can put people forward; individuals are not able to put themselves forward to NICE.

An HTA is a very formal process that can feel quite overwhelming. All participants need to sign a confidentiality agreement and receive some very detailed paperwork.

We give our representatives clear instructions on what to expect. NICE also has an excellent patient involvement team who put people at their ease and talk them clearly through the process. They are very good at keeping everyone updated at every stage of the process, which can stretch out over time.

Patient representatives share their experience of treatment for lymphoma at the meeting in order to put the assessment in context; adding a human element and putting the patient in the mind of the group who are looking at very technical and economic information.

People who have represented us to date have given very positive feedback about the whole experience of an HTA.



It must be emphasised that the committee is not swayed by emotions, but are making a practical, evidence- and economics-based decision.

Do Lymphoma Action receive feedback and can we appeal?

We are involved throughout. Stakeholders are usually told within a week of the meeting whether NICE recommends the treatment, or if further investigations are needed. It is fairly common for a drug not to be recommended at the appraisal consultation document stage, with many going on to need further evidence before the final appraisal document is prepared.

We are invited to submit further evidence at that stage. Although we can appeal a decision, there has

not been the need to, as most drugs relating to the treatment of lymphoma have been recommended by NICE.

Do Lymphoma Action publish the results of HTAs?

As soon as the final NICE recommendation has been published, Lymphoma Action will publish this on the news section of their website. We also report on the decisions of the Scottish Medicines Consortium.

How long is it before the treatment is available on the NHS?

If NICE recommends a drug or treatment through its technology appraisals programme, the NHS is legally obliged to fund it and must make sure it is available within 3 months

of its date of publication (unless otherwise specified).

The NHS Constitution says that patients have the right to drugs and treatments that are recommended by NICE for use in the NHS, if their doctor believes they are clinically appropriate.

At Lymphoma Action we believe it is important to be involved in health technology assessments and we are proud to ensure the patient voice is heard.

We have a video about health technology assessments you can watch at: www.lymphoma-action.org.uk/HTA



Normality after lockdown – the magic three (with some sunshine added)

Consultant Psychotherapist, Sean Orford, gives his insights into what might make people feel better at this unusual time.

Although we were all forced into lockdown together, this experience has varied widely between people.

For those who were shielding - as many reading this were - it may well have been a reminder that you are living with a health issue. For those with children, there was the responsibility of home schooling and keeping children occupied and motivated. Relationships may have come under some strain as we adjusted to spending all our time together, when in non-COVID times we typically went to work, or did leisure pursuits outside of the family unit.

We are social animals who like being in groups and doing things. While technology is great and has allowed us to keep in touch, seeing someone on screen or talking to them on the phone is not the same as actually being with them, touching them and smelling them.

Daily pattern and routines

We are creatures of habit. Our days, weeks and months have a rhythm that creates our feeling of normality. For some, the first 4 weeks may have been an opportunity to catch up on things – reading, TV, exercise, decluttering or doing some decorating. At about the fourth week this may have changed into frustration and cabin fever.

It is important to re-establish daily patterns and rhythms to improve our wellbeing. I believe the essential ingredients for this are sleep, diet and exercise. I will also share my views on the power of sunlight.

Getting a good sleep routine

We all need different amounts of sleep, but getting a good night's sleep of around 7 to 9 hours is important for physical and emotional health.

Have you noticed that when you go on holiday your sleep pattern changes? You tend to go to bed later and get up later. You don't have the usual commitments, so your routine has been allowed to change. Since lockdown many people have developed a holiday sleep pattern. But getting back to a good routine is important for your wellbeing.

To help your sleep pattern, go to bed at a regular time. Avoid devices like televisions, phones and tablets prior to bed time. It may help to set your alarm for your normal waking time, even if you feel tired. Getting up to your alarm will help your pattern shift back.

Don't forget to eat a healthy diet

Unfortunately, many people have put on weight during lockdown. For some it's a lack of exercise, others have found that they are snacking, drinking more alcohol or having extra caffeine drinks. Try to get back to regular meals at regular times.

Find time for exercise

We are designed to move. As hunter gatherers we are designed to be in motion, so long periods of sitting will not help us feel good. Keeping your body moving for some part of the day has a direct effect on your brain.

Try to make a plan to get up every hour and take a short walk around; you'll be surprised at how much better you will feel. Many exercises are available, including gentle ones you can do while sitting. The important thing is to move your body and if you can, raise your heart rate for 20 minutes a day. Your brain will release a mass of endorphins which will make you feel better.

The power of sunlight

You may have heard of SAD (seasonal affective disorder) where people feel sadder in the winter than in the summer. This is because of serotonin, which acts on nearly all of the brain cells and influences mood, sleep, appetite, decision making and social behaviour. Low serotonin levels may contribute to feeling down or becoming depressed. Antidepressants work because they raise the level of serotonin and make us feel better.

Vitamin D, which you get from being out in the sun, promotes serotonin production. Unless you have been able to spend time in a garden in the sunlight, you may find that your vitamin D levels are low. This may make you feel flat or down. If you think this is the case, talk to your doctor about possible supplements to increase your levels of vitamin D.

Getting outdoors in the sunlight really does help, but there are some foods that have high levels that might help too:

- oily fish, such as salmon, sardines, herring and mackerel and cod liver oil
- fortified food (breakfast cereals, oatmeal, some cows' milks and some orange juices)
- mushrooms - the only plant-based food that helps. Mushrooms can make vitamin D when exposed to UV light, so try leaving mushrooms out in the sun before using.

Remembered with love



Do something wonderful

Legacies are vital to us.
Please remember Lymphoma Action in your will.

Lymphoma Action volunteer Linda explains why her parents chose to leave a gift to Lymphoma Action in their will.

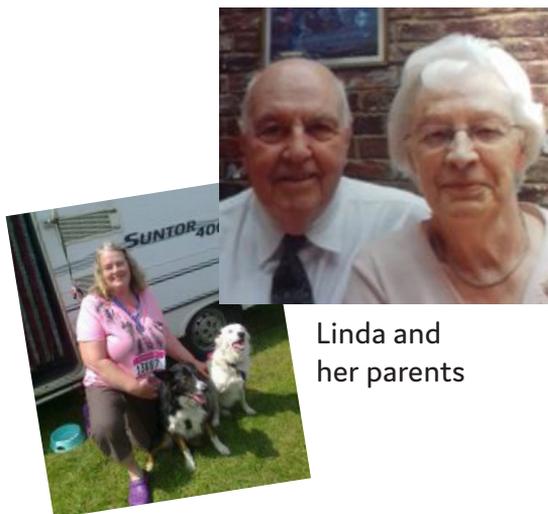
'My mum and dad married in July 1952, after knowing each other since childhood. My mum had a few part-time office jobs, while bringing up my sister and me. My dad joined the police force and worked his way up to Inspector before he retired, and then he worked as a civilian at the local police headquarters.

When I was diagnosed with non-Hodgkin lymphoma in August 2000, at age 46, my parents were both shocked. My mum came with me to my first appointment after my diagnosis and came with me on the first day of each cycle of chemo as well as check-ups. Her love and support meant so much to me.

My treatment has spanned over 20 years, and sadly my mum developed Alzheimer's. Eventually it became impossible for her to come with me for my check-ups. It felt strange, and still does, going on my own.

Both my dad and mum died within 6 months of one another last year. I miss them so very much. But I was pleasantly surprised that they remembered Lymphoma Action in their wills. They had remembered how the Charity had been there for me in my darkest times - at my diagnosis, later when my lymphoma returned as extranodal, when I needed to start chemotherapy and later when I was treated with radiotherapy.

I have been so lucky to live 20 years since my diagnosis in August 2000. I was happy to start the Lymphoma Action Support Group in Nottingham and also become a Buddy. Thinking about my wonderful parents, I am delighted that their legacy will help others affected by lymphoma.'

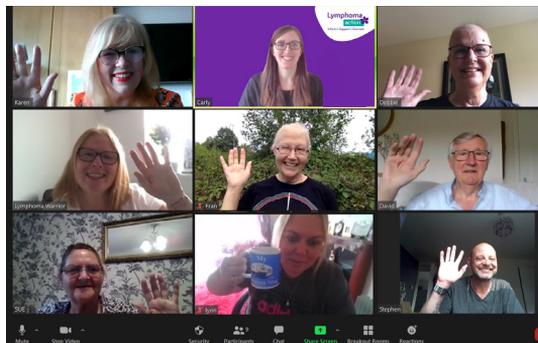


Linda and her parents

Whatever the size of your gift, you can help us to be there for future generations affected by lymphoma. If you would like to discuss leaving a gift in your will, or request a legacy pack, please contact us on **01296 619400** or fundraising@lymphoma-action.org.uk. For more information visit our website at www.lymphoma-action.org.uk/Legacy Please note: we are unable to give legal advice.

Everybody's talking ...

Although the coronavirus pandemic meant that our face-to-face support groups had to be suspended, we responded quickly. We extended our closed regional Facebook group to cover the whole of the UK, and we also launched UK-wide virtual support meetings.



Karen Bonell, Lymphoma Action Regional Development Manager for the North told us: 'Our UK-wide Facebook group and virtual support groups connect people affected by lymphoma from all over the UK. Whether you are newly diagnosed, or many years on from the treatment, the group offers valuable peer support at a challenging time.'

Don't just take Karen's word for it. Here's what our users are saying...

...about our virtual support groups

'I found the virtual meeting really comforting. To actually see others on Zoom made it more personal. I wasn't sure about it at first, opening up to others you don't know, but I felt better afterwards.' Anne

'I didn't feel intimidated in showing my newly bald head to the group. They were so supportive and encouraging and knew exactly what I was going through.' Sharon

'We joined the support group to know that we are not alone. Meetings are proving a vital link.' Rob

'Both the Facebook group and the virtual meetings have been invaluable especially when shielding. You know that there will always be a listening ear.' Jean

...about our Facebook group

'I honestly don't think I'd have coped emotionally without being able to read other experiences and feedback on my own posts. This group has been invaluable to me and my hubby.' Dee

'This group has helped me tremendously come to terms with my diagnosis. If I've had any worries, I've asked the group.' Steve

'Things that I was scared to ask, or didn't want to burden my family with, have been shared on here. Having people who know how you feel, shared the same experiences and are a shoulder to cry on, have got me through chemo and lockdown and kept me sane.' Joanne

Find out more at www.lymphoma-action.org.uk/OnlineSupport



Reality Trauma

Carly, diagnosed with Hodgkin lymphoma

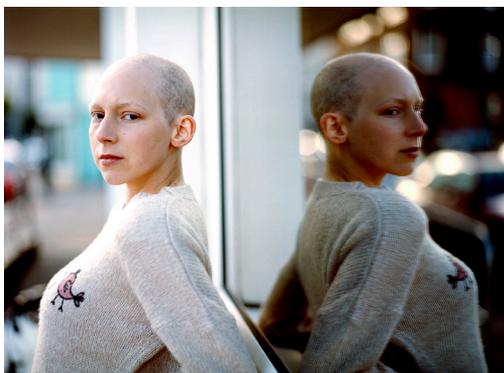
In 2011, I was a 26-year-old in my final year of a BA Photography course in London. I was ambitious and looking forward to a creative future. I had a project that I had wanted to realise; I was fascinated by the lives of people living in the Downtown Eastside area of Vancouver and wanted to document them and the community they lived in. I would go on to spend 5 weeks working in freezing conditions, photographing and interviewing people with drug and alcohol addiction and people with illnesses or disabilities.

Little did I know, when I got on a plane to Canada from the UK, that I had a debilitating and life-threatening illness myself.

My health had gradually got worse over a period of 6 to 9 months. I had a violent, constant cough, a lack of appetite and a pain in my chest and back. In addition, I was gradually losing weight. I had visited many clinics and doctors and had been given varying diagnoses from asthma to needing a physiotherapist. I put my pains down to carrying heavy camera equipment.



Since I couldn't get a refund on my flight, I decided to take the risk. On my return to the UK in January 2012, I arrived at my parents' home coughing up blood. My mother had tears in her eyes and we both knew that my life would change from that moment on. My local doctor advised me to go to Accident and Emergency and I subsequently spent several weeks being examined and tested. Eventually, after a lung biopsy, I was diagnosed with Hodgkin lymphoma, stage 4B, and a tumour was found to be spreading through almost half of my chest.



During this period I created a series of photographic self-portraits that I entitled 'Reality Trauma'. I was overwhelmed by the chemotherapy treatment, which lasted for 6 months, and I felt a real need to record my journey and document my life as it changed so drastically. My body became a shell and I could do nothing but wait for every treatment to end. The image of who I thought I was became unfamiliar, almost alien. I was losing my hair and so much weight I was unable to recognise my reflection in the mirror, which I avoided at all costs. The hospital staff and doctors became like a family to me. My identity felt crushed, yet I didn't mind because I knew this perception of a helpless human being was not really me. Inside I was strong, determined and hopeful... and terrified.

My life slowed down to just concentrating on getting through each moment; drug to drug, endless exams, needles, biopsies and tubes. The cure seemed to be as dangerous as the disease. A meditative focus on the small things that mattered really helped. I found a great deal of comfort in talking to those in hospital who'd had similar experiences and spending time with family and friends. For me, this experience can best be recalled through my photography. Nothing can take me back to my time with cancer like a photograph, that moment in its entirety, as if I were there again, re-living the sensations, the feelings and the fears.

'My photographs remind me of my ability to endure.'

We do not give ourselves the credit for fighting some of life's toughest battles. This period in my life is evidence for me that no matter what life throws at us, we can get through it. We are more than survivors, we are more than we think we are. We are always changing and becoming something else. Change can be the biggest part of who we think we are and my series of pictures are a moment in time. These photographs evoke some painful memories for me, but they also remind me of the huge capacity of my own body to endure.



Our books are available to order free of charge

Our award-winning books can help you better understand your diagnosis, treatment and life beyond lymphoma. Download or order printed copies free of charge, at www.lymphoma-action.org.uk/Books

Books available:

- Introduction to lymphoma
- Hodgkin lymphoma
- High-grade non-Hodgkin lymphoma (revised)
- Low-grade non-Hodgkin lymphoma (revised)
- Chronic lymphocytic leukaemia (CLL) and small lymphocytic lymphoma (SLL)
- Active monitoring (watch and wait) for lymphoma
- Living with lymphoma
- Young person's guide to lymphoma
- Autologous stem cell transplant
- Clinical trials
- Easy Read books – Finding out you have lymphoma
Watch and wait for lymphoma
Treatment for lymphoma
After treatment for lymphoma
- Tom has lymphoma (for primary school-aged children)