

Leukaemia Matters



WINTER EDITION 2018



Coming full circle

Laura had all the common symptoms of leukaemia, but it took two weeks to get her diagnosis of acute myeloid leukaemia. Now three years on, Laura shares her journey and how she's doing now.

Page 15

Benefits of exercise

Page 25-27

In This Issue



6 50th campaign



9 Looking back at BCAM



14 Dyer's dinner dance



20 Staying healthy this winter



23 Claire Tunnacliffe



28 Clinical trials



Hello,

Welcome to the Winter issue of our magazine!

It's been a busy year for Leukaemia Care, highlighted by the success of our Spot Leukaemia campaign, which reached over 125 million people and helped to educate them on the symptoms of leukaemia.

However, we also sadly lost two members of the Leukaemia Care team this year: Ann Ashley, a long-standing previous volunteer and trustee, and Zelma Roberts (known to many as Zelma Hunt), Care and Support Advisor at Leukaemia Care. I would like to extend my heartfelt condolences to their loved ones. You can read more about the important contributions Ann and Zelma made to Leukaemia Care on pages four and five.

This issue is an online-only exclusive and is packed full of information to help you through the winter months.

Inside you'll find tips from both our nurse, Fiona Heath, and Patient Advocacy Healthcare Liaison Officer and leukaemia patient, Nick York, on looking after yourself this wintertime. You can also find an informative article on the benefits of exercise for leukaemia patients.

Our cover star in this issue is Laura Mattei, who is currently in remission from acute myeloid leukaemia (AML). She tells us about how she's rebuilt her life after her diagnosis.

Merry Christmas and a Happy New Year!

Christopher Matthews-Maxwell
Chairman

Keep up with the latest news and patient stories online. You can find us at: www.leukaemiacare.org.uk



Patient Services News

Catch up on the latest news from our Patient Services team.



Launch of new buddy scheme

Earlier this year, we launched our buddy scheme specifically for chronic lymphocytic leukaemia (CLL) patients.

After the success of the scheme, we'll soon be launching a new one aimed solely at acute leukaemia patients.

If you're an acute patient and would like to find out more, get in touch with our Buddy Co-ordinator, Kay Drew, by emailing kay.drew@leukaemiacare.org.uk, or call her on 01905 755 977.

Support groups

We have a number of support groups meeting in early 2019, including some brand-new groups.

New groups for January, February and March include:

- Milton Keynes Haematology Support Group on 22nd January 2019
- Nottingham Chronic Lymphocytic Leukaemia Support Group on 30th January 2019

- Glasgow South Haematology Support Group on 21st February 2019
- Cambridge Chronic Lymphocytic Leukaemia Support Group on 5th March 2019
- Taunton Haematology Support Group on 25th March 2019

See what other groups are meeting in the New Year on our website at <http://bit.ly/LCSupportGroups>.

Don't miss our final fatigue information day

This year, we took our fatigue information day on the road to Oxford, Cardiff and Sheffield.

Hosted by fatigue expert Dr Anne Johnson, the days were a great success. So, make sure you book your free place for our final stop in Edinburgh on 16th March 2019.

Book your place at <http://bit.ly/EdinburghFatigueInfoDay>.

Support over Christmas

Leukaemia Care helpline

Our helpline will be closed from 4.30pm on **Friday 21st December** until normal service resumes at 9:00am on **Wednesday 2nd January**.

Our nurse will still be available on the evening of Friday 21st December from 7pm - 10pm. Please call freephone 08088 010 444.

Our website will be available throughout the Christmas period if you need any information.

Leukaemia Care office

Our office will be closed from 5:30pm on Friday 21st December until 9:00am on Wednesday 2nd January.

Please head to our website to contact our team and we will respond when our office re-opens in the New Year.



In memory of Ann Ashley

In loving memory of



Ann Ashley

28th December 1938 - 7th October 2018

We are saddened to report the death of long-term friend, volunteer and supporter of Leukaemia Care, Rosalind Ann Ashley, known fondly to the charity as Ann.

Ann became involved with the charity in the early 70s following her husband's diagnosis and was highly involved with us from that time.

In her role as a volunteer regional co-ordinator, Ann supported families affected by leukaemia in her local area and kept in touch with them for many years. She was a kind,

supportive voice at the end of the phone for people facing some of the most difficult times in their lives.

Later, Ann joined the Leukaemia Care trustee board and was passionate about making the patients' voice heard.

Any time that Ann learnt of a member of the Leukaemia Care staff team becoming pregnant, she would knit a beautiful pram blanket and send it to Head Office. These items are still treasured today.

At one point in time, Leukaemia Care had in excess of 200 volunteers. Ann would handwrite a Christmas card each year to show her appreciation for everything they were doing.

After leaving the trustee board, Ann continued to be there for the charity. From the weekly phone calls to hear updates as to what the charity was doing, to selling her famous homemade pickled onions to raise money each Christmas, her support was unwavering.

In 2016, Ann was invited to the Queen's Garden Party in

recognition of the number of donations of blood she had made throughout her lifetime. A year later, Ann was presented with a Mayor's civic award from the Mayor of Havering, recognising her years of dedicated service in supporting Leukaemia Care.

Outside of her charitable work, Ann enjoyed travelling and visited Australia on multiple occasions. Ann had no children of her own, but doted on her Godchildren and family members.

Ann passed away in October 2018 after a short illness. She will be missed very much by everybody at the charity.

Remembering Zelma Roberts



We are saddened to report the passing of a much-loved member of the Leukaemia Care team, Zelma Roberts, formerly known as Zelma Hunt, and known to many as simply Zeli.

Zeli joined Leukaemia Care as part of the twilight team, answering the helpline during the evening. She then moved onto the day shift and played a big part in the charity's financial assistance programme, making sure people received much-needed support.

She was passionate about helping people, always going the extra mile. If she didn't know the information they needed, she would go above and beyond to find out all she could. She would listen with intent and ensure the person she was speaking to had 100% of her attention, empowering them to move on with their journey whether they were a carer or a patient.

She was always the glue that kept the Patient Services team running smoothly, always at the centre of things, recognising

when someone was down and needed picking up. She was always there to make the team laugh with her comic timing and quick wit!

She started and ran the Worcester Haematology Support Group supporting many patients through good and bad times, ensuring there were always speakers of interest and arranging amazing Christmas parties, including Secret Santa and quizzes.

She also organised all the admin for the support groups, from sending out posters and flyers to ensuring everyone had invites and knew what was going on.

Zeli ran a tight ship with our helpline volunteers, making sure our line was covered by volunteers throughout the evening. She enjoyed the communication with them, finding out how they were and what they and their families were up to.

She made the team cry with laughter with her observations, outlook on life and the zest for living she had. If there was something she wanted to do, nothing would get in her way. She was determined, strong and forthright. One of a kind.

Zeli passed away in November 2018 and will be greatly missed by the team.

Leukaemia Care is turning 50

Get ready for our new campaign coming in 2019.

That's right, 50 years of supporting patients and their families and helping them to receive the right information and advice.

Whilst you are counting down to Christmas, we will be counting down to our golden anniversary year of 2019. As this milestone is fast approaching us, what better time to reflect back and remember the various ways patients, volunteers and committee members have helped over the years to make Leukaemia Care the organisation it is today.

From the founding members, who had the foresight to realise just how much support patients and families need after receiving a blood cancer diagnosis, to past chairmen, treasurers and trustees who have ensured that the society moved in the right direction, and of course the nurses and committed staff who help us to run our national support groups and helpline.

Throughout the New Year, we will be showing our thanks to these many helping hands and continuing to raise awareness of blood cancer.

History of Leukaemia Care

Leukaemia Care was first registered as a charity by the name of the "Leukaemia Society" on 11th September 1969. It all began when a small group of parents, whose children had leukaemia, were sat around a kitchen table in Holland Park, London. Here they decided to set up one of the first ever support groups to help others going through a similar situation. 50 years later, what started as one has grown to over 40 support groups spread across the UK, and the Leukaemia Society has transformed into a national charity with a passionate team of employees, trustees and volunteers.



Whilst you are counting down to Christmas, we will be counting down to our golden anniversary year of 2019.



Since the very start, the Leukaemia Care magazine has always been an essential part of what we do as a charity, and in many ways has acted as the

focal point for those closely involved with the charity. This was certainly the case before the emergence of the internet.

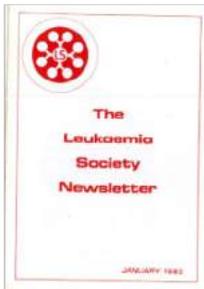
The quarterly magazine as we know it today first began in 1969 as a one-page stencilled newsheet and was the work of Syd and Nancy Westgate from Newcastle upon-Tyne. It then expanded into a small booklet, and with the inclusion of advertising evolved into the Caring & Sharing magazine. As you can see from the timeline on the next page, there has been a fairly large reshuffling of names since this time. With your help, we settled on the current name "Leukaemia Matters" earlier this year.

History of Leukaemia

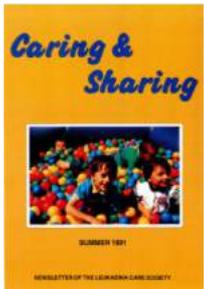
The first detailed account of leukaemia was provided by Rudolf Virchow in 1845, who named the disease Leukämie in German, which he formed from the Greek leukos, meaning "white", and haima, meaning "blood".

During the 1800s, there were very few treatment options available for leukaemia and the disease was almost always fatal; the only effective therapy at that time being 'Fowler's Solution', or potassium

1982



1991



1998



2007



2010



2018



arsenite, which was later discontinued due to its toxicity to healthy blood cells. The turn of the 20th century saw the discovery of radioactivity, and hence, radiotherapy was swiftly adopted as a method of treatment for leukaemia.

With the centenary of the World War 1 Armistice coming to a close this November, the horror of The Great War is fresh in our minds. Ironically, these dark days rather unexpectedly lead to the next breakthrough in the treatment of leukaemia: chemotherapy.

Mustard gas was just one of many poisoned gases developed by Fritz Haber used in WW1. When working desperately to find an antidote prior to World War 2, two American doctors noticed that WW1 veterans who had been exposed to mustard gas had a significantly low white blood cell count. This led to the hypothesis that the mustard gas could be used to kill leukaemic white blood cells. Many cytotoxic anti-cancer drugs used today, such as chlorambucil, are directly derived from the chemical structure of mustard gas.

Around the same time the Leukaemia Society emerged, combination therapy was being employed as the next best method for treating leukaemia. This involved combining drugs from different groups to yield better results. The 1990s then saw the emergence of targeted therapies, such as imatinib (Glivec) for chronic myeloid leukaemia, which work in a subtler manner than standard chemotherapy drugs by selectively killing cancer cells, rather than killing all cells.

Today, immunotherapy and gene therapy sit at the forefront of research and are providing promising results in clinical trials. This, along with the recent NHS approval of CAR-T therapy for the treatment of children with acute lymphoblastic leukaemia, is perhaps a taste of a new era to come for leukaemia treatments.

Survival since the sixties

Unsurprisingly, the improvements in medicines since Leukaemia Care was founded has meant that as with most cancers, the survival rates have improved massively. Leukaemia Care first began as a support system solely for the parents of children with leukaemia, but it quickly went on to expand during the 1970s to include adult patients. Somewhat fittingly, this shift in agenda was very much the result of a giant improvement in medical treatment during the 60s for childhood leukaemias. In 1960, less than 1 in 10 children with ALL survived into adulthood, whereas nearly 8 in 10 survived in 2010. And the progress didn't stop at childhood leukaemia. From 1971 to 2010, the five-year survival in adults increased from 34% to nearly 70% when taking into account all types of leukaemia.

The Future and our 50th Year Campaign

Whilst developments in medical therapies have continued to boost survival rates in leukaemia, late diagnosis is now a significant barrier to these effective treatments, as it can mean the cancer has more time to develop to a stage where it is difficult to treat.

The Spot Leukaemia campaign

was devised in 2017 to ensure that more people are aware of the symptoms of leukaemia and therefore can be diagnosed earlier. Next year, as part of our golden anniversary, we will be running a year-long #SpotLeukaemia campaign to continue raising awareness of the signs and symptoms of leukaemia amongst both the public and primary healthcare professionals to further improve these survival rates. We'll be focussing on bringing clarity to the symptoms that often precede a blood cancer diagnosis, as their vague nature can often lead to an initial misdiagnosis. This will involve weekly social media posts of in-depth articles and videos about the main symptoms of leukaemia, to help everyone to spot leukaemia.

The other side of our yearlong campaign will be focussing on what we've spent the last 50 years doing: making sure patients and their loved ones get the advice and support they need. Across social media we will be highlighting fifty key issues faced by blood cancer patients, one each week throughout the year. The first of our monthly themes, in January, will focus on the struggles of exercise and diet for patients, perhaps especially appropriate for many of us following the indulgent festive period.

We also hope to put a face to these issues by sharing fifty patient stories all year round, so please get involved by telling us your personal experience of coping with a blood cancer, whether you are a patient,

family member or carer.

Finally, our Advocacy Officer, Charlotte Martin, will be hosting "Meet The Experts" once a month as part of her Facebook Live events. This will give you the opportunity to ask questions and gain advice directly from the professionals, ranging anywhere from Clinical Nurse Specialists to Nutritionists to Benefits Advisors. The experts are here to help you deal with the issues we are raising throughout the year, so please interact with them and get your queries answered.

Learn more about Spot Leukaemia on our website: www.spotleukaemia.org.uk



PICTURE: GARY LINEKER WAS A PATRON OF LEUKAEMIA CARE FROM 1999 TO 2013.

Looking back at BCAM

This September was Blood Cancer Awareness Month, and we once again held our Spot Leukaemia campaign. Find out what we got up to during the month.

Back in the Summer issue of Leukaemia Matters, we urged you to get involved in our Spot Leukaemia campaign during Blood Cancer Awareness Month in September. Well, you did in your hundreds and thousands, even your millions! Thank you all for your support.

Spot Leukaemia aims to improve both public and GP awareness of the signs and symptoms of leukaemia. Early diagnosis saves lives. We want the public to get checked out quicker if they have worrying symptoms and for GPs to know when to refer for a blood test, which is all that is needed to diagnose or rule out a blood cancer.

The Spot Leukaemia campaign this year built on the activities of our first campaign in 2017. We started Spot Leukaemia following the results of our patient survey, which showed that many blood cancer patients did not think their symptoms were a sign of cancer, nor did they know anything about leukaemia prior to diagnosis. We recognise that knowledge among the public does not change quickly, so we decided to repeat the campaign this year and remind everyone of its importance.

Here's an update on all the activities that went on during the campaign this year.

Social media, hashtags and storytelling

Every day in September, we shared a story, either written or a video, from a patient who had been diagnosed with a blood cancer. We asked them to share their experience of symptoms before diagnosis and what they wish they had known when they were first unwell. This made a huge impact, with three stories reaching the national press.

In all, we reached 113 million people via our national press coverage. We could not be more grateful for patients that share their stories with us, it really helps us to spread our messages through the words of those who have experienced or are living with a blood cancer.

As well as individual stories, we shared videos and articles, including ones to highlight the six most common symptoms of leukaemia, alongside our campaign hashtag #SpotLeukaemia. The hashtag reached 3 million people on Twitter alone, whilst our campaign overview video was viewed by 95,500 people.

Sharing the message face to face

Another way the public contributed to our campaign was by ordering our merchandise and flyers to spread the word. 5000 of our symptoms cards were ordered and shared among communities, raising

awareness of the symptoms most common in each age group.

Symptoms cards were also delivered to GP surgeries, together with flyers to advertise our dedicated GP workshop on leukaemia, held in London. Similarly, we asked healthcare professionals, including dentists and pharmacists, to create awareness boards with our posters to help share the symptoms of blood cancers with their patients and colleagues.

Travelling the country

The Patient Advocacy team also embarked on a roadshow in September, visiting areas that we had identified as having low awareness of the symptoms of leukaemia. We set up our marquee on the high street, chatted to people about Spot Leukaemia and handed out goody bags with our spotty merchandise. We also asked people to take photos wearing spotty outfits, to help spread the Spot Leukaemia message. In total we visited six places: Camden in London, Oxford, Birmingham, Liverpool, Nottingham and York. The public were extremely friendly, especially when we were battling the unseasonably windy weather! Thank you also to those who came to hand out goody bags with us through rain and sunshine, your time was much appreciated.



PICTURE: NICK YORK, OUR PATIENT ADVOCACY HEALTHCARE LIAISON OFFICER, HOSTED HIS SPOTTY DOG WALK FOR THE SECOND YEAR IN A ROW.

Fundraising

You came out in your droves this September, holding events from bake sales to spotty dog walks to colour runs. Fundraisers included Northwick Manor Primary School, who raised £603 at their spotty day, Tracy Murphy, who raised £120 at her coffee morning, and Craig and Jane Munro, who raised £2,500 at their charity football match!

Trips to London: celebrating the campaign and raising awareness among GPs

On the evening of the 19th of September, we held this year's celebration of the Spot Leukaemia campaign at 30 Euston Square, headquarters of the Royal College of General Practitioners (RCGP). Everyone who had contributed to the campaign was invited as we shared the #SpotLeukaemia message, heard from patient Kate Stallard and shared the results of the 2017/18 patient survey.

Euston Square was a fitting location for the celebration as this year's campaign ramped up the focus on raising awareness of leukaemia amongst GPs. Just five days after the celebration event, we returned to RCGP to hold our second ever GP education day. 50 GPs from the London area joined us to hear from haematologists, statisticians, fellow GPs and patients about the importance of recognising leukaemia symptoms and caring for blood cancer patients in their surgeries. The event was a huge success and future events are planned around the country for 2019.

Make everything Spotty!

Throughout September, we took any opportunity to make things spotty! Our support groups dressed up in spots and enjoyed spotty snacks. Our Head Office then held a spotty dress down day and a spotty pizza buffet.

We would also like to thank the eight football clubs that kindly

allowed us to advertise in their programs to raise awareness of the campaign. This allowed us to reach 450,000 football fans with our message.

All in all, Spot Leukaemia was a huge success for 2018, and we couldn't have done it without all our volunteers and fundraisers. You can see more about our next campaign on pages 6-8. If you would like to get involved with Leukaemia Care, please contact us at one of the following email addresses:

- If you have an idea for a fundraising activity, please contact: fundraising@leukaemiacare.org.uk
- If you would like to share your story or help us share our campaign messages, please contact: campaigns@leukaemiacare.org.uk
- Or you can call 01905 755977 and ask to speak to the relevant team.

Campaigns Corner

New member of the team

In October, the Patient Advocacy team welcomed Fergus Metcalf, our new Campaigns Officer. Fergus will be responsible for organising the campaign for our 50th year, which you can read more about on pages 6-8.

Drug updates

Gemtuzumab ozagamicin

Gemtuzumab ozagamicin has been approved by the National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) for use in patients with previously untreated CD33 positive acute myeloid leukaemia (AML), except acute promyelocytic leukaemia (APL or APML) patients. The brand name for this drug is Mylotarg and it is manufactured by Pfizer.

The drug has also been restricted for use in patients with favourable or intermediate cytogenetics.

Cytogenetics is the study of changes in the chromosomes within cells; certain genetic changes can change how patients might respond to treatment. The restriction has been put in place because the clinical trials for Mylotarg showed it was only effective on those with favourable or intermediate cytogenetics.

Importantly, it will also be available to patients who haven't yet found out their cytogenetic status, so no one who might benefit has their

treatment delayed.

You can read our response to the approval here: <http://bit.ly/GemtuzumabNICE>.

Tisagenlecleucel-T

In the last issue, we discussed how Tisagenlecleucel-T (Kymriah, manufactured by Novartis) had been approved for use by the European Medicines Agency (EMA). It has now been approved for use in England by NICE. The process of approving Kymriah for use in Scotland is ongoing.



Cytogenetics is the study of changes in the chromosomes within cells.



Kymriah is the first chimeric antigen receptor T (CAR-T) therapy approved for use in the UK. CAR-T is a process that takes T-cells (a cell of the immune system) and changes their genes in a way that makes the cells fight cancerous cells, rather than foreign bodies as they normally do. This is an entirely new and innovative technique and so will require training before it can be implemented fully in the NHS.

You can find out more about CAR-T in our Know Your Rights toolkit, which is available on our website: <http://bit.ly/CAR-T-TherapyToolkit>.

New advisory panels

Throughout October and November, the team held meetings with both patients and haematologists to create two new advisory panels. The aim of these meetings was to gain a more detailed insight into the experiences of patients throughout their leukaemia journey, to complement the data driven information we got from our surveys.

We have previously had a medical panel at Leukaemia Care, but this has been redesigned so experts in each type of leukaemia meet separately (AML, CML, CLL, ALL and other blood cancers). This will allow us to drill deeper into the issues facing each group of patients.

The patient advisory panels are an entirely new idea for Leukaemia Care and have been a great success. So far, we have held meetings for CML, CLL and other blood cancer patients (with patients who have rarer types of leukaemia, MPNs or MDS). Patients were able to share their opinions on our work over lunch and give us ideas on what activities we could do to address the issues they and their fellow leukaemia patients face.

The panels will convene twice a year to discuss the progress of Leukaemia Care's work. Please get in contact with Charlotte Martin at advocacy@leukaemiacare.org.uk if you would like more information

BIG IDEAS FOR BETTER HEALTH

Join the conversation on Twitter
#BI4BH
@abbvieUK



PICTURE: FERGUS METCALF AT THE BIG IDEAS FOR BETTER HEALTH AWARDS.

on joining either panel. We are particularly interested in hearing from acute leukaemia patients (AML, ALL or APL), whatever stage of your journey you are at.

Spotlight on travel insurance

Our Advocacy Caseworker, Charlotte, attended a roundtable at the offices of the Financial Conduct Authority in London this November. This was to discuss a new signposting service to help people with pre-existing medical conditions access affordable travel insurance much more easily.

Also attending the meeting were insurance industry representatives and other charities; all commented on where the service should be advertised and how to make the process as simple as possible for customers. Charlotte will continue to input into the development process;

do get in touch at advocacy@leukaemicare.org.uk if you would like to share your views on travel insurance.

Events

Patient Advocacy Director champions patient's experiences

Zack Pemberton-Whiteley, Leukaemia Care's Patient Advocacy Director, has been out and about sharing our work with the wider community over the last couple of months.

He spoke about our patient survey data at both the All-Party Parliamentary Group on Blood Cancer and at a European summit about acute leukaemia. He shared the results of the survey, why they are useful for our work and the importance of patient data and patient advocacy. You can see the results of our patient survey here: [https://www.leukaemicare.org.uk/get-](https://www.leukaemicare.org.uk/get-involved/our-campaigns/living-with-leukaemia/)

[involved/our-campaigns/living-with-leukaemia/](https://www.leukaemicare.org.uk/get-involved/our-campaigns/living-with-leukaemia/).

Zack also spoke at a NICE training event in October on the topic of patient involvement in the health technology appraisal process. This is the process where NICE decides which medicines the NHS in England should fund. Leukaemia Care regularly share anonymised survey data and patient stories with NICE to help them make their decisions and Zack shared with the committee why we feel patients are a key voice to be heard in the decision process.

If you have been a part of a clinical trial and would like to participate in the approval process for the drug you have used, please get in touch at advocacy@leukaemicare.org.uk.

ASH 2018

The annual meeting of the American Society of



Peter Hillmen, MBChB, FRCP, FRCPath, PhD University of Leeds, Leeds, UK

PICTURE: DEBORAH SIMS AND
PROFESSOR PETER HILLMEN
DISCUSS DATA PRESENTED AT ASH.

Haematology took place from 29th November to 4th December in San Diego, California. Our Patient Advocacy Director, Zack Pemberton-Whiteley attended to hear the latest updates from the haematology world.

We also asked leading clinicians to speak to us about the big news from the conference. You can find their videos on our YouTube channel: <http://bit.ly/YouTube-LC>.

Finalists at the Big Ideas for Better Health Awards

Our Campaigns Officer, Fergus Metcalf, attended the awards ceremony for the Big Ideas for Better Health Awards, which are sponsored by the pharmaceutical company Abbvie. Leukaemia Care was nominated in the category of "Driving prevention and early intervention" for our #SpotLeukaemia campaign. We were finalists and Fergus was presented with a certificate for our achievements. You

can find out more about the #SpotLeukaemia Campaign at



The patient advisory panels are an entirely new idea for Leukaemia Care and have been a great success.



www.spotleukaemia.org.uk.

Britain Against Cancer 2018

This annual meeting is organised by the All-Party Parliamentary Group on Cancer, currently chaired by Nic Dakin MP. The event brings together policy makers, charities, NHS providers and those affected by cancer to discuss how we can all address the challenges faced by cancer patients. It is the biggest one-day cancer conference in the UK.

Advocacy Officer, Charlotte

Martin, and Patient Advocacy and Healthcare Liaison Officer, Nick York, attended and heard the thoughts of a range of people, such as the Today programme presenter and cancer patient Nick Robinson, Macmillan CEO Lynda Thomas and Shadow Secretary of State for Health and Social Care, Jonathan Ashworth. They also advertised the Spot Leukaemia campaign. Have a look at our Twitter [@LeukaemiaCareUK](https://twitter.com/LeukaemiaCareUK) for more of their thoughts on the day.

To find out more and get involved, send an email to advocacy@leukaemiacare.org.uk or call the Campaigns and Advocacy team on **01905 755977**.



The Dyer's dinner dance

This November, the Dyer family hosted a dinner dance in memory of beloved father Charlie Dyer, and in the process they set a new record with the most money raised at one single event for Leukaemia Care. Rosie Dyer talks more about the event here.

On 27th October 2017, our dad Charlie Dyer passed away following a very short 10-day battle with Burkitt's lymphoma. Myself, my brother Oliver, our mum Annette and my brother's partner Charlene wanted to honour Dad's one-year anniversary with a dinner dance with all of our friends and family to celebrate his life, but also to help raise money for Leukaemia Care.

The event was called The Charlie Dyer Memorial Dinner Dance and was held on Saturday 3rd November at The Lion Inn in Boreham, which was our Dad's favourite restaurant. There were 160 guests in attendance.

We sold tickets for the evening which included a three-course meal, half a bottle of wine and a welcome drink. During the dinner we played a game of Kings and Queens to raise some additional money, and we also held a raffle and an auction on the night. We approached a number of local businesses for raffle prizes. They were so generous, and we ended up giving away over 30 raffle prizes.

For the auction, we were able to

source a number of great prizes, including meals in London, tickets in a box at the O2, boxing tickets, cricket tickets and signed football shirts from West Ham, Liverpool and Arsenal. There were a number of Dad's friends who were unable to make it on the evening who also donated money.

The evening itself went by in a flash. We had a lot of running around to do as we wanted to greet all of the guests, and then during dinner we were selling raffle tickets and getting everything in place for the auction. Luckily, we had an amazing MC for the evening (Dave Dennison, an old friend of Dad's) so that meant that the raffle and auction ran really smoothly. We couldn't believe how much money the auction raised (almost £10,000).

Once the meal and raffle and auction were out of the way, we could let our hair down and dance and catch up with all of our friends. It was a lot of hard work and took months of preparation, but we wouldn't change that for the world. We ended the night on a high knowing that we had raised over

£17,000 for a charity that is now really close to our hearts. Plus, so many people were coming up to us saying how great the evening had been and what a fitting tribute it was to Dad, so all the hard work was worth it to hear that. Our dad was the life and soul of the party, so what better way to remember him a year on than with a party.

The total amount raised on the evening was £17,138.94. We were completely overwhelmed by the amount and couldn't quite believe it. Our target was £10,000, so we went above and beyond what we wanted to raise. We were so proud when Claire Merritt told us that this is the most anyone has ever raised for the charity with a single event.

Because of that, we would love to make it a yearly event. We appreciate that we wouldn't necessarily be able to host a dinner dance every year but would like to do an event of some kind each year to help remember Dad, but also to raise money for Leukaemia Care. So many people on the night kept asking us if we will do it again next year, so that must be a good sign.

Laura Mattei: Coming full circle

Laura Mattei had all the common symptoms of leukaemia, including fatigue, breathlessness and bleeding, but it took two weeks to get her diagnosis of acute myeloid leukaemia. Now three years on, Laura shares her journey and how she's doing now.

In late August 2015, I started feeling weak and breathless. I remember going out and about in London in the last weekend of August with friends visiting from Italy and not being able to walk for long without feeling extremely tired. The following week I developed high fever and flu-like symptoms. I went to see my GP on Tuesday 1st September 2015, and they told me I had flu and advised me to rest, drink a lot and take paracetamol.

On Thursday 3rd September, my fever was still high and, as I had to start a new job at an estate agency in Wimbledon on that day, I went to see my GP again. This time they prescribed me antibiotics; that helped bring down my fever pretty quickly. I also agreed with my new employer I would start on Monday 7th September.

On Saturday evening, I then had a serious nosebleed. I was quite worried as blood came out of my nose in thick clots, so I called 111 – my GP surgery was closed at that time. They advised me to go to A&E as a "nosebleed can be nothing and everything". Even though the nosebleed stopped after a while, my husband and I still went to our local hospital, St George's NHS Trust in Tooting, London, on the same night. The doctor who saw me said most likely my

nosebleed was a consequence of the cough linked to the flu. He did not think a blood test was needed, something I now believe would have been very useful and appropriate to spot my leukaemia earlier.

On Monday 7th September 2015, I started my new job. I was still feeling weak and tired but thought this was a consequence of the flu and the antibiotics I was still taking.

On Wednesday 9th September, when I arrived home from work, I noticed some unexplained bruises on my right hand and lower limbs. That worried me, but as I was not aware of the symptoms of blood cancer at that time, I did not think of anything really bad. I was also very excited with my new job and did not think of doing some searches on Google.

The following morning, on Thursday 10th September, the bruises were still there and, when brushing my teeth, I saw many red papules inside my mouth. I started thinking something wasn't quite right but, as I was off on Friday (I was required to work on Saturdays), I decided not to go and see the doctor straight away. I also did not want to take a day off sick after only four days in my new job!

On Friday 11th September, I went to see my GP with my husband at 8am before he went to work; we are lucky as our surgery is just in front of our home in Wimbledon Park. I did not have an appointment, but when I explained my situation to reception, one of the doctors saw me straight away. He asked me lots of questions, carried out a very thorough check and decided to take a blood test himself.

After lunch, I received a call from the GP surgery. They told me my blood levels were very low and wanted to refer me to a haematologist at St George's Hospital for further investigation. They also asked me to go to the surgery to take the referral letter and, if possible, not to go to the hospital alone. I called my husband and waited for him at the surgery. We went together to St George's at about 6pm on Friday 11th September. The referral letter from the GP mentioned an Hb count of 64 and a platelet count of 7.

When I arrived at St George's Hospital, I had a new blood test taken and was visited by a haematologist. After a couple of hours, he told me the results were in line with those of the previous test and I needed blood and platelet transfusions

With thanks to Abby Taylor of
www.abbytaylorphotography.co.uk
for the photos





straight away to avoid the risks of internal bleeding. He also said I had many abnormal (he called them "immature") white cells in my blood and needed to be admitted to the hospital to carry out further tests.

I had a bone marrow biopsy on Monday 14th September. On Wednesday 16th September I was given a first, partial response: the lead consultant of the haematology team at St George's Hospital, Dr Fenella Willis, told my family and I that I had either acute myeloid leukaemia (AML) or a myelodysplastic syndrome (MDS) but needed the complete results of the bone marrow test to diagnose me. I was finally told I had AML on Friday 18th September, seven days after being admitted to the hospital and two weeks since I'd started developing symptoms.

That day Dr Willis told me she had "bad and good news": the bad news was that it was indeed acute myeloid leukaemia; the good was that it was curable and was associated with a good prognosis because of its particular sub-type, t(8;21) abnormality. She explained I had to start treatment ASAP and they were planning to use high dose chemotherapy as I was healthy and had no other conditions.

I started my treatment on Tuesday 22nd September. I was lucky as I tolerated chemotherapy well and only occasionally experienced

some of the worst side effects normally related to it such as nausea, diarrhoea, mouth ulcers and vomiting. I vomited badly only a couple of nights and had painful mouth ulcers only during the fourth cycle.

I lost my hair after the first cycle but that didn't really bother me, as I knew it would come back at the end of treatment. Honestly, I did not think losing my hair was a big issue while I was fighting against such a terrible disease!

As it normally happens, I developed infections during every cycle after becoming neutropenic. I had high fever each time and became increasingly resistant to standard antibiotics, so they had to treat me with stronger ones. During my third cycle, I developed high fever over Christmas and experienced vaginal bleeding, mild nosebleeds and petechiae rash over my right shin. I had to go back again to the hospital for a few days between the third and fourth cycle to treat an episode of influenza A.

Ten days after my last dose of chemo, I started experiencing breath shortages and found it increasingly difficult to talk. Chest x-ray findings were consistent with PCP, a particular and very aggressive form of chest infection that is normally seen in immunosuppressed patients. Doctors were quite worried and treated me with oxygen and high dose antibiotics that I had

to be given via the PICC line; after taking many medicines every day over the previous five months, I couldn't swallow pills, especially the big antibiotics. That meant I had to have a second line inserted in my right arm and receive intravenous drugs 24 hours a day for almost a week! This was definitely the worst period of my treatment, also because I knew it was almost over and couldn't wait to go back home.

After each cycle, I had the opportunity to go home for a couple of weeks. I really enjoyed these short breaks as I could spend some time with my husband and family outside the hospital and do something relatively "normal". Although I was told to be careful as my immune system was very weak, advice I did not always follow to the letter, to be completely honest!

I spent Christmas and New Year's Eve in a side room. That was a new and challenging experience for my family and me, but we managed it quite well. My husband set up a nice Christmas tree in my room and added lots of decorations to the walls. Unfortunately, I was not able to enjoy all this on Christmas Day as I had a fever of nearly 39, and my sister, who had just arrived from Italy with her husband to spend Christmas with me, was at A&E with serious issues to her balance system! My husband also organised a mini-party in the room on New Year's Eve with



some yummy treats so we could celebrate together the coming of the New Year, and hope for a better period.

I was very lucky as I received fantastic support throughout the entire period from my family and friends. I never was or felt alone during treatment. My husband visited me for a couple of hours every evening after work on weekdays and spent every weekend in the hospital. Nurses at the ward told me I was lucky to have such a dedicated husband!

My parents moved to London from Italy in early October 2015, despite not speaking a word of English, and remained until the 27th December 2015. Unfortunately, they had to go back to Tuscany after Christmas as my father had a heart attack in December while at the hospital and needed to recover from that. Mum and Dad were great: they came to visit me every day in the morning and stayed until late afternoon. They baked cakes, Italian focaccia and cookies and gave them not only to me but to doctors and nurses too. They become very popular in the ward for that!

My sister came up to London from Italy several times and was in contact with me daily on Skype or WhatsApp. She jumped on a flight the day after I was admitted to the hospital in September and did the same when I had pneumonia at the end of my fourth cycle of chemotherapy.

Not only my family and friends offered me constant warmth and support, both practical and psychological. Since the very first day I was admitted to St George's Hospital in September 2016 - and during all the following months - I always felt extremely reassured by the high professionalism, human approach and great commitment showed by doctors

and staff. They could not have been more kind, supportive and knowledgeable. At a time when the NHS is often criticised for its shortcomings, I can only thank St George's Hospital and Gordon Smith Ward for the caring and dedicated support I received that ultimately saved my life.

I completed my fourth cycle of high dose chemotherapy in February 2016 and left St George's Hospital on 1st March 2016. I am in complete remission since. I have my regular checks every three months now and a venesection each month to bring down my ferritin level, which was extremely high after completing my treatment and is now almost back to normal. I feel well and live a normal life. I know I'm still at risk of relapse for at least another couple of years, but I think positive and don't let this affect my desire to plan for the future and live life to the fullest.

My experience with leukaemia and the months spent at St George's Hospital, interacting with and being cared for by care and medical staff, did not only help me understand the invaluable importance of healthcare professionals' work, but also pushed me to reconsider my own priorities, and to pursue a new career in care.

I still work in care and genuinely love and am proud of my new role. I know it may sound weird, but I really think my experience with leukaemia gave me the strength and motivation to look into myself and find my true path in life.

In November 2017 I won the Best Newcomer Award at the regional Great London Care Awards 2017. When I was called on stage to collect the award in front of over 500 care professionals from all around London, I remembered my long days in the side room, the bad infections I experienced

and the aggressive treatment I had to go through to fight that terrible disease, and thought life can be truly a wonderful thing.

Recently, I was offered a healthcare position at Mary Seacole Ward (specialist ward for elderly rehabilitation) at Queen's Mary Hospital in Roehampton. This is absolutely amazing as Queen's Mary Hospital is part of St George's University Hospitals NHS Foundation Trust, the hospital where I was successfully treated for my AML.

You can imagine how important this is for me. Doing the job I have chosen to do as part of my new path in life in the place that saved me from leukaemia is like closing a circle. I must confess working within the St George's network has always been my long-term goal since I started thinking about my new career in healthcare while I was going through treatment. But honestly, I was not expecting this to happen so quickly! After winning the Award last year, this is another dream come true.

Sometimes, great things come from very bad ones. As the proverb goes, every cloud has a silver lining. You just need to see the glass half full rather than half empty even in the darkest moments and never give up hope. Like everything really important, my experience with leukaemia is not only negative. It helped me understand what I really wanted to do and start a new, rewarding career. It also motivated my husband to become a regular blood donor and join the Bone Marrow Registry.

I feel happier and more at ease with myself now and I am definitely stronger. I enjoy what life brings and I have learnt to put things into perspective. I am a survivor and I know I can face every challenge and fight back as I did with cancer.

Staying healthy this winter

Nick York, Patient Advocacy Healthcare Liaison Officer and chronic lymphocytic leukaemia patient, and our Nurse Advisor Fiona, are here to share their tips for the colder months.

As winter hits home and the crowds gather, those with compromised immune systems may fear travelling by public transport or joining in with the festivities. How can we improve our chances of staying healthy through the winter?

Here are some top tips for blood cancer patients:

1. Keep moving

Staying in shape with exercise can prevent your general health from deteriorating. It will help you enjoy general activities, as it can reduce fatigue, and prepare you for treatment. Regular exercise also helps to control your weight and boosts your immune system. It also has psychological benefits.

You can find out more about the benefits of exercise when you [click here](#).

2. Stay up-to-date with vaccinations

Blood cancer patients are immune compromised and less able to fight off infection. As a result, vaccinations are well worth having. Speak to your doctor about getting vaccinations such as the flu jab, and ask close friends and family if they'll have the jab too. It is the best way to protect against

flu and other infections, such as bronchitis and pneumonia.

You can find out more about the flu vaccine in our blog by [clicking here](#).



If you have reduced immunity, it is recommended that you have the flu vaccine.



3. Employ strategies to avoid catching infections

Start with frequent hand washing and use of hand sanitiser or antibacterial wipes. Handwashing destroys bugs that you may have picked up from surfaces touched by other people, such as light switches and door handles.

Avoid touching your eyes, nose and mouth. Be careful when opening and closing doors, flushing loos, etc. by using a tissue. Be cautious around possible sources of infection.

It is also important to keep the house and any household items such as cups, glasses and towels clean, especially if someone in your house is ill. If you get a cold, use disposable

tissues and throw them away after each use.

4. Stay warm

Make sure you dress for winter! Wrap up warm when out and about if you're taking part in the festivities. Wear thick socks to bed too and keep a hot water bottle on hand at home.

However, if you're symptomatic and suffering from night sweats, wear breathable, cotton clothing to bed that will keep you warm when you need it, but also absorb any moisture so you can easily change clothes if needs be.

5. Eat well

When it's cold and dark outside, it can be tempting to fill up on unhealthy comfort food. However, it's important to ensure you still have a healthy diet and include five portions of fruit and veg a day.

If you're neutropenic, make sure you take care with how your food is prepared and what you eat. You can find more advice by [clicking here](#).

Otherwise, make sure to eat a balanced diet and try to follow a few general healthy-eating principles. You can read more information on a balanced diet and maintaining a healthy



weight when you [click here](#).

6. Stay hydrated

It's important that you drink plenty of fluids to remain hydrated. Being dehydrated means your body has a harder time repairing itself and fighting infection.

7. Get plenty of rest and sleep

The benefits of sleep are endless, so make sure you're getting enough! Getting enough undisturbed sleep is vital for staying healthy in the winter months. It's recommended that adults have seven to nine hours of sleep a night. Aim for about eight hours of sleep a night and try to go to bed and get up about the same time every day.

If you're struggling to sleep, speak to your doctor.

8. Avoid stress

Stress can compromise your immune system, as it heightens the amount of cortisol (the stress hormone) in your blood. Whilst a little bit of cortisol can be beneficial in helping you to deal with stressful situations,

too much over a long period of time can lower your immune system and also increase inflammation.

There is no easy cure for stress, but there are simple things you can do to help reduce it. Many people find adding meditation, yoga, breathing exercises or mindfulness techniques into their day helps to calm them down and feel more relaxed. Try practicing these activities to reduce your levels of stress, or consider seeing a therapist. You can find out more about mindfulness techniques for blood cancer patients [here](#), and information on finding a therapist [here](#).

9. Keep on top of your dental work

Poor dental health can pull you down and is an avenue for persistent, opportune infection. Make sure you report any issues to your dentist.

10. Symptoms? See your GP

If you come down with an infection or you're experiencing symptoms of any kind, speak to your GP sooner rather than later.

11. Moderate your festive alcohol consumption

Whilst you might be tempted to knock back a few mulled wines now the nights are getting darker, remember alcohol can make you dehydrated (see tip #6) and can also interfere with some medicines, such as antibiotics.



If you're symptomatic and suffering from night sweats, wear breathable, cotton clothing to bed that will keep you warm when you need it.



So, try not to overdo it, and make sure you speak to your GP for advice on alcohol consumption.

12. Review your medications

As Christmas approaches, take stock of your medication and make sure you have enough to last the festive period.



13. Make sure you're not vitamin deficient

As UV levels dip in the Northern hemisphere and days get shorter, your vitamin levels may require balancing, and your sleep and waking cycles may become disrupted. The lack of sun means your brain produces more of a hormone called melatonin, which makes you sleepy. Open your blinds or curtains as soon as you can to let more sunlight into your home, and get outdoors in natural daylight as much as possible. In addition, investigate Vitamin B and D tests to check you're not deficient.

14. Stop smoking

Smokers have an increased risk of developing pneumonia, as well as other chest infections – and so do children whose

parents smoke.

If you have a blood cancer

If you have leukaemia, lymphoma or myeloma, you may be more vulnerable to infections, especially in the winter months.



The benefits of sleep are endless, so make sure you're getting enough! Getting enough undisturbed sleep is vital for staying healthy in the winter months.



Cancer patients who are receiving chemotherapy are more vulnerable to infections as their white blood cell count is low.

If you are neutropenic (low white cell count) and you feel unwell with a fever, it is important that you seek help straight away without delay.

If you have any more questions, call our helpline on **08088 010 444**. Check **page 3** to see when we're open during the festive period, or visit our website at www.leukaemiacare.org.uk.

Claire Tunnacliffe: Distance travelled

Claire Tunnacliffe has taken on the London Marathon twice for Leukaemia Care. In the process, she's raised over £10,000 for all those affected by blood cancer. Here, she describes her journey, and how she took up running in memory of her dad.

It is perhaps a strange confession, but my relationship with both running and grief has a lot to do with numbers. Counting, adding, subtracting, dividing, multiplying. Counting towards a moment - a run, a race, a death, an anniversary - and then counting away. Setting a fundraising target, and then watching the numbers add up. Dates, times, distances, pace. Miles run in training, or in a race. Miles run this week, month, year. Distance travelled since Dad died, in both mileage and time.

Numbers mean that the memories don't get lost; mean that I don't get lost. Numbers anchor into place the pivotal dates, sometimes imperceptible, others seismic, all engraved onto the grey matter of my brain, that made my world suddenly hinge in a different way, the axis of my world suddenly spinning at a different angle: Dad's diagnosis of acute myeloid leukaemia; the time (10:49), the day he died (29th November 2011); 23 years old; my first half, my first marathon, my first ultra; 25, 26, 28 years old; going from a 4:17 to 3:53 marathon; fundraising £500, £2,000, £4,000.

I remember hitting £5,000 and thinking, in that moment, could

it be possible to reach £10,000 by the time I am 30? Two years to go. In between, I fantasise about being faster, stronger. In between, I fantasise about finishing and that Dad is there both watching me and running beside me. In between, I am angry when my body won't go faster than I want it to. I am angry because I can't run better when he can no longer, he who used to run every day.

£7,000, £8,000, £9,000 for Leukaemia Care. Then, I'm 30 and I'm tired. In the space of 4.5 years I've run 10 half marathons, multiple 10Ks, 5 marathons, 1 did not finish (DNF), 1 ultra marathon, 1000s of miles in training. A string of PB's. And then, something broke. My body gave way, and injuries crept in again and again, forcing me to slow, eventually to stop. My body physically creaking under the distance travelled since his death, the lines around my eyes dug a little deeper.

I talk a lot about the reparative effects running has had on me. It has taught me important lessons about trust, on showing up for myself, healing and grieving. However, for me, running also occupies a complicated and confusing space, being both a form of therapy and a well of self-

criticism and judgement. Numbers may have spurred my growth, success, of hitting PBs and fundraising targets, but equally they became tiny barriers to maintain. And even more so than the physical, I mentally struggled. It seemed that I couldn't outrun myself anymore and I became unforgiving when my body hurt, or was tired, or just didn't want to. Running became both release and trap.

On the 22nd of April 2018, I laced up for my second London Marathon despite not having been able to train for months. Full disclosure: my mental health isn't great either. But I'm here, I'm 30, and that morning fundraising hit £10,808 for Leukaemia Care. The numbers have added up.

I've not told many people this, but I speak to my Dad when I run. I wonder how many of us dig up our ghosts in these moments. I dig deep and think of him here. I slow to a shuffle and my legs are screaming, but I don't stop. When it really, really hurts, the pain becomes a strange portal, where I roll an incantation I have practiced during many races before: come on papa, come on. This unlikely daughter of his, the runner he never knew me to be.

Claire Tunnacliffe and friends
at the Virgin Money London Marathon 2018.



Benefits of exercise

After a blood cancer diagnosis, keeping fit and active might be the last thing on your mind, but exercise can benefit both your treatment and recovery. Here, our Nurse Advisor, Fiona Heath, explains more.

There are many benefits to being physically fit whilst undergoing cancer treatment for leukaemia, and in the recovery period too. It can reduce stress and give you more energy, and a large amount of research and information is available on these benefits.

What sort of exercise should you do?

You need to ensure you choose something you enjoy which is also appropriate for your level of fitness, diagnosis and circumstance. There is no point doing something you have no interest in as most people find it hard enough getting motivated to exercise in the first place.

When you feel able to exercise, you should increase your exercise activities gradually. At first, you may feel much more tired than usual, but over time this will improve. Regular exercise can help increase strength, maintain muscle mass and promote flexibility. It also helps to alleviate fatigue, and activities that include weight bearing exercise can also help to improve bone density and reduce the risk of bone thinning (osteoporosis).

The key to exercising is to plan it into your schedule and find as many ways as possible to incorporate it into your everyday life. Aim to work up to doing

30 minutes of exercise four to five times a week if you can. If you find it difficult to do 30 minutes at one time, break it down into 10-minute blocks and increase it as your strength and endurance improves.

The extent and rigor of the exercise that you do will depend on your current activity levels and physical condition. Walking for 20 minutes each day is an excellent choice of exercise for almost anyone. Mild exercise like walking is very good for you and helps to alleviate fatigue. Start exercising slowly and gradually build up to a more strenuous workout. Don't push yourself to the point where you are very tired and out of breath. Staying active during the day will also help encourage normal fatigue at night, making it easier to sleep.



You need to ensure you choose something you enjoy.



Although exercise has many benefits for leukaemia patients, it is important to always check with your healthcare professional before starting any exercise program and to be aware that you may need to take some precautions.



It is important to start at a low level of intensity and work up gradually.



Precautions

Blood Counts:

Low red blood cells (anaemia):

Red blood cells carry oxygen to your organs and tissues. When they are low, they may not be able to keep up with the increased demand put on your body during exercise. You may notice that you get tired much more easily and might have difficulty catching your breath when you exert yourself. During times when you have low red blood cell counts, you should reduce the intensity of your workouts or avoid them altogether depending on the advice of your medical team.

Low white blood cells

(neutropenia): When your white blood cells counts are low, you have a decreased ability to fight off infections. At this time, you should avoid crowds and keep your exercise routine closer to home. Gyms, swimming pools and changing rooms increase your risk of being exposed to a virus or bacteria that can make you unwell. If you have a fever, don't push yourself to exercise.



Take some time off to help your body heal and recuperate.

Low platelet counts (thrombocytopenia): Platelets are responsible for forming clots in your body. When your platelets are low, you are more at risk of bleeding and bruising. For this reason, you should avoid contact sports and activities in which you may be at high risk of falls or injury. You may choose to use resistance bands instead of heavy weights that you could drop.

Peripheral neuropathy

Some people have loss of sensation, or feelings of pins and needles, in their hands and feet due to cancer treatments. This is called peripheral neuropathy. If you have this, it might be better to use a stationary bike than to do other types of weight bearing exercise.

Central Venous Catheter

If you have a central venous catheter (CVC) you will need to make sure it is well secured before exercise activities. A tunnelled CVC can be tucked

into a sports bra or taped or fastened to your body. Peripheral CVC (PICC lines) should be taped or wrapped securely to prevent them from becoming dislodged.

After you have completed your treatment

The NHS currently recommends that adults aged 19 to 64 should try to be active daily and should do:

- At least 150 minutes of moderate aerobic activity such as cycling or brisk walking every week and
- Strength exercises on two or more days a week that work all the major muscles (legs, hips, back, abdomen, chest, shoulders and arms).



During times when you have low red blood cell counts, you should reduce the intensity of your workouts or avoid them altogether.



This should be viewed as a target to work towards. It is important to start at a low level of intensity and work up gradually, especially if you are recovering from treatment.

Another benefit of keeping your fitness up after treatment is that it can reduce longer term risks such as heart disease, which may be associated with some treatments. It can also increase the likelihood that you are fit enough for optimum treatment in the future, should you need additional treatment.

You can find even more exercise tips on our website. Just head to: <https://www.leukaemiacare.org.uk/support-and-information/information-about-blood-cancer/living-well-with-leukaemia/exercise/>



The EASI-SWITCH trial

Our Nurse Advisor, Angela, has years of experience in clinical trials. In this latest article, she's looking at a study for the early switch to oral antibiotic therapy in patients with low risk neutropenic sepsis.

This study is available for eligible patients who may require intravenous antibiotic therapy during their chemotherapy treatment. The study will be open for the next three years from hospitals across the UK and will plan to recruit around 600 patients.

It is being supported by the Belfast Health and Social Care Trust and funded by the National Institute for Health Research Health Technology Assessment Programme.

Neutropenia refers to a low number of neutrophils, a type of white blood cell that is important for fighting infection. Neutropenic sepsis is an infection that may develop when there is a low white blood cell or neutrophil count. It is a common complication of chemotherapy treatment in cancer patients because, in addition to killing cancer cells, chemotherapy also affects the bone marrow which makes new blood cells including neutrophils.

Patients can potentially become very unwell if an infection is left untreated when they have a low white blood cell count as they don't have the normal immune response to fight the infection. It is therefore important that patients are treated urgently with antibiotics to try and start fighting the infection

immediately. Treatment normally involves intravenous antibiotics (through a drip) for several days.

Studies so far have not been rigorous enough to inform current treatment. The aim of this study is to see if low risk neutropenic sepsis patients do not need as long a course of intravenous antibiotics; that an early switch from intravenous to oral antibiotics within the first day of treatment is as effective as intravenous antibiotics for a longer time.

Patients can be identified as 'low risk' by doctors calculating a special score, known as a MASCC score, when they first arrive in hospital to see if it is suitable for the patient to be offered information for the antibiotic study.

There is some evidence from small studies that low risk patients can be safely switched from intravenous to oral (tablet) antibiotics within the first day of treatment.

What does the study involve?

Patients will have already been started on intravenous antibiotics when admitted to hospital. To get a reliable result as to whether early oral antibiotics are just as effective as longer intravenous antibiotics, a comparison

is done by putting patients into two different antibiotic treatment groups using a technique called randomisation. The two antibiotic groups are:

1. Standard intravenous antibiotic treatment
2. Early switch oral antibiotics

A computer program selects which antibiotic group each patient will be in and will be told the result. Neither the patient or their doctor can choose which group they will receive.

For this study, there will be a 50% chance of being in the group receiving earlier oral antibiotics.

Each patient will need to be eligible in order to take part in the study. This will be discussed with their consultant. Following written consent, patients will be asked to:

- Provide one additional research blood sample
- Keep a diary of any symptoms/side effects at home
- Complete three short questionnaires and two short telephone interviews. This will be at two and four weeks after hospital admission, at the hospital or as a telephone discussion with the research nurse.



What treatments are being studied

Antibiotic treatment

Patients who are receiving standard intravenous antibiotic treatment will continue to receive intravenous antibiotics for at least two days. They will receive the standard intravenous antibiotics that their hospital normally uses to treat neutropenic sepsis e.g. Tazocin or Meropenem.

The doctor looking after you will decide how long each patient will need to stay on intravenous antibiotics and if or when they can switch to oral antibiotics.

If laboratory tests suggest a different antibiotic would be better for the infection, or the temperature isn't quickly settling, the doctor looking after each patient would change the patient's antibiotics and explain their reasons for doing so.

Patients who are receiving the early switch oral antibiotics will switch over at 12-24 hours of having intravenous antibiotics to two oral antibiotics. The antibiotic tablets that are being used in this study are Ciprofloxacin, which is taken twice a day, and Co-

amoxiclav, which is given three times a day. The antibiotic tablets will need to be taken for five days of antibiotic treatment in total.

All of the antibiotics used in this study are currently routinely used in the UK and no experimental drugs will be used. If a patient's temperature doesn't settle within two days of switching to oral antibiotics (i.e. within three days of starting antibiotics) this may indicate that the early switch to oral antibiotics has not worked well enough at treating the infection fully. The doctor may then change the antibiotics depending on what they think is the best treatment for each individual patient and will discuss this.

The consultant will decide when discharge home is appropriate and give clear advice as to what antibiotic treatment needs to be completed at home.

Patients will be asked to complete a diary when they get home from hospital. This needs to be filled for two weeks after leaving hospital.

This will include:

- Temperature recordings, details and instructions will be given by the research team.

- All doses of tablet antibiotics taken.
- Any possible side effects from the antibiotics.
- Any new medicines started.
- Other significant events including being readmitted to hospital, developing a further infection or if any further antibiotics are required.

Patients will be followed up at two- and four-weeks following discharge home as part of this study by their consultant and research team. This will be planned around clinic visits and may involve a telephone discussion and completion of patient questionnaires.

A summary of this clinical study will be available on: <http://www.ClinicalTrials.gov>

Talk to your medical team to find out more about this study and to see if you're eligible to take part.



**Merry
Christmas from
everyone at
Leukaemia Care**