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# Leukaemia Matters



WINTER EDITION 2019

## A friend for life

Nicky shares her story and gives thanks to her donor and now lifelong friend, Annette.

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**Hello,**

Welcome to the Winter issue of our magazine!

It's been another busy year for Leukaemia Care as we celebrated our 50th anniversary. We spent much of the year working harder than ever to provide support and advice to those affected by blood cancer, and we were delighted to have our work recognised by a special visit from HRH Duchess of Gloucester, GCVO.

You can learn more about what we've been up to during this eventful year by turning to page four.

Elsewhere in this issue, we're featuring an uplifting story from acute myeloid leukaemia (AML) patient Nicky Turkoz, who shares how a stem cell transplant not only saved her life, but also brought her closer to her donor and now lifelong friend, Annette.

Also inside this issue, you can learn about our special charity Christmas appeal with the Telegraph, as well as read an honest account on survivorship from acute promyelocytic leukaemia (APL) patient Thea.

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](http://www.leukaemiacare.org.uk)



# Patient Services News

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



## Buddy scheme expansion

Could you be a buddy to someone this Christmas? Or perhaps you're looking to talk to someone who understands what you're going through at this time of year?

We have a number of buddy schemes open to patients, including:

- Acute myeloid leukaemia (AML)
- Acute lymphoblastic leukaemia (ALL)
- Acute promyelocytic leukaemia (APL)
- Chronic lymphocytic leukaemia (CLL)
- Chronic myeloid leukaemia (CML)
- Chronic myelomonocytic leukaemia (CMML)
- Hairy Cell leukaemia (HCL)
- Essential thrombocythaemia (ET)
- Polycythaemia vera (PV)
- Myelodysplastic syndromes (MDS)
- Carer for someone with blood cancer

If you're interested in becoming a buddy, or you'd like to be matched with one, get in touch with our Buddy Coordinator, Kay Drew, on [kay.drew@leukaemicare.org.uk](mailto:kay.drew@leukaemicare.org.uk) or call **08088 010 444**.

## Book now for our Glasgow patient information day

We have one more city to visit as part of our current series of information days, so join us in Glasgow on 7th March 2020 for insightful talks on topics such as fatigue, diet and exercise and the emotional effects of blood cancer.

Missed out on our previous information days? Can't make Glasgow? Don't worry, we'll have more information days coming up in the New Year, so keep your eyes peeled for details!

To book your free place for Glasgow, go to: <http://bit.ly/PatientInformationDays>, or call the team on **08088 010 444**.

## Apply for our Hospital Travel Fund

Our Hospital Travel Fund provides grants of up to £200 for patients and families affected by leukaemia to put towards hospital travel costs.

The fund operates on a monthly basis. There is no closing date,

awards are distributed on a first-come, first-served basis until the fund is depleted each month.

For more information - including what we will fund and eligibility criteria - and to apply, head to our website at: <http://bit.ly/HospitalTravelFund>



For more information, you can contact the team on **08088 010 444**, or email [support@leukaemicare.org.uk](mailto:support@leukaemicare.org.uk). You can also find all our support groups on our website at [www.leukaemicare.org.uk](http://www.leukaemicare.org.uk).

# A Year in Campaigns

Find out what we got up to for our 50th anniversary.

## LC50: what a year!

This year, Leukaemia Care turned 50 years old. Throughout the year, we have not only been celebrating our achievements since 1969, but also using the year to highlight issues that still affect blood cancer patients today.

Leukaemia Care started in 1967 as a group of parents gathering around a kitchen table to discuss how they could support others affected by leukaemia. All had children affected by a diagnosis of leukaemia but were determined to support each other and turn their pain into something positive for others in the future. They turned this into an official charity, registering in 1969. You can learn more about the origins of the charity on our website here: <http://bit.ly/LCFoundingMembers>

## How have we celebrated our 50th year?

Whilst treatments for all types of leukaemia have come on leaps and bounds, and so survival rates increase, learning to live with or after blood cancer becomes more important. For the first part of the year, we dedicated our social media, newsletters and magazines to raising awareness of these ongoing issues, using the hashtag #LC50. We also provided practical tips to help patients deal with these challenges day to day.

In January, we addressed diet and exercise, asking chronic myeloid leukaemia (CML) patient and fitness fanatic, Drew Laird, to give you all tips on getting back to exercise post-diagnosis.

In February, we talked about sex and relationships. Our Nurse Advisor, Angie, joined Patient Advocacy Manager, Charlotte, on our podcast to remind patients to be open and honest with their loved ones and that no question to your nurse is a silly question.

Patients shared their struggles with fertility issues in March, sharing stories of heartbreak and of surprise.

In May, we chatted with Usha Grieves from Compassion in Dying about the ultimate taboo in any cancer patient's life, and why we should all talk about dying more. To help with these conversations, we developed new toolkits to help you plan funerals, write wills or communicate your wishes with those around you.

In the summer months, we highlighted the challenges for blood cancer patients when it comes to enjoying the wonderful weather and a chance to relax. We gave advice on staying safe in the sun and produced a new Advocacy Toolkit to help you find the best value travel insurance possible.

Additionally, throughout the year, we repeated our Spot Leukaemia messages.

Diagnosing leukaemia earlier has been shown to improve outcomes and survival rates of patients, which is why we focus on this every year. Our hashtag #SpotLeukaemia reached over 11.5 million people in 2019, double the number we reached last year.

Throughout the year, these messages helped Leukaemia Care reach over 2.5 million people online, and more in print. More importantly, the campaign helped raise awareness of the ways in which a diagnosis of blood cancer affects every aspect of a patient's life and emphasises the need for more support.

## The biggest Spot Leukaemia yet

Our anniversary of registration falls on the 11th of September, which, as many of you will know, coincides with Blood Cancer Awareness Month, during which we run our Spot Leukaemia campaign. While we kept up the message of Spot Leukaemia year-round, we really stepped up the campaign to combine a celebration of the charity with the biggest September campaign yet! We did this by advertising as widely as possible, to reach as many people as possible.

- We lit up major buildings up and down the country, including Blackpool Tower, Belfast City Hall and the BT Tower in London.
- We handed out 400,000



PICTURE: HRH THE DUCHESS OF GLOUCESTER UNVEILS A PLAQUE COMMEMORATING HER VISIT

branded pharmacy bags across 400 independent pharmacies, encouraging those who may be feeling under the weather or thinking about their health to get their symptoms checked out at the GP.

- We advertised on billboards and bus shelters, with an estimated 750,000 views across the week they were displayed.
- Our wonderful volunteers handed out over 5,000 symptoms cards, sharing them with friends, family, colleagues, libraries, community groups and GP surgeries across the country.
- We shared podcasts with famous faces who have been affected by blood cancer, including ex-England footballer Geoff Thomas, WWE wrestler Roman Reigns

and ex-chief medical officer and haematologist Professor Dame Sally Davies.

Patients shared their diagnosis stories with us, highlighting symptoms to look out for and encouraging others to pay closer attention to their health. 36 patients told their stories, with 15 doing so on camera. Sharing these stories, as well as other posts and podcasts, helped us encourage 58,000 people to visit the Spot Leukaemia website to learn more about the campaign.

We also held a campaign event in the Houses of Parliament, hosted by Henry Smith MP. This annual event helps us raise awareness of the Spot Leukaemia campaign with MPs, policymakers, other charities, the press and more, to spread the message as far and wide as possible. It was also a wonderful opportunity to thank those who help the charity each year, from

patients and their families to nurses and doctors.

### A Royal visit to celebrate our 50th anniversary

To round off a fantastic 50th celebration year, we were honoured to be joined by HRH the Duchess of Gloucester, GCVO at our head office in Worcester. The Duchess was invited to meet staff, patients and healthcare professionals involved in our work. She heard how the work of Leukaemia Care, whilst having changed over the years, is still as vital as ever in supporting those affected by blood cancer. The Duchess also revealed a plaque marking our 50th year and commemorating the visit for the future.

Find out more about our LC50 campaign here: <http://bit.ly/LC50Campaign>

# Campaigns Corner

## The general election: what does this mean for blood cancer patients?

The general election on 12th December 2019 has provided us with a chance to set out what we think blood cancer patients need from the next government. We have done this, in conjunction with 28 other cancer charities, in the "One Voice" manifesto. We are calling on the next government to improve support for cancer patients, stick to targets to improve early diagnosis of blood cancer and make sure there are enough nurses, GPs and other healthcare professionals working in the NHS to properly care for cancer patients. You can read the full manifesto here: <http://po.st/YLppBC>.

The election also means the All-Party Parliamentary Group (APPG) on Blood Cancer, previously led by Henry Smith MP, has been disbanded until MPs have been elected. The APPG was a great chance for charities to work with MPs and directly relay what we believe are the key issues that could be addressed by parliamentary processes. We will keep you all updated if and when it reforms.

## Out and about

As always, the team have been out and about to raise awareness of issues facing blood cancer patients.

In September, our Patient Advocacy and Healthcare Liaison Officer, Nick York,

organised the CLL Horizons meeting in Edinburgh. This was a part of his role as the chair of CLL Advocates Network, the international organisation that represents and brings together chronic lymphocytic leukaemia (CLL) patients and the charities that support them across the globe. Our Patient Advocacy Director, Zack Pemberton-Whiteley, presented on the importance of using evidence when advocating for change, using the example of our "Living with Leukaemia" survey. Additionally, Patient Advocacy Manager, Charlotte Martin, shared thoughts from the UK about where barriers to accessing treatments still exist, despite a comprehensive public health system being in place in the UK. We also heard from delegates from the US, Africa and Australia, with the hope that the lives of patients with CLL will be improved across the globe.

Additionally, CLL Horizons was fortunate to join with the UK CLL Forum meeting, allowing delegates to hear from leading clinicians - Professor Fegan, Professor Schuh and Dr Walewska - and debate the big challenges for CLL clinicians and patients alike. Prof Fegan gave an update on immune system challenges for CLL patients, and Prof Schuh discussed in which order different treatments should be given, noting that this is becoming more complicated with more and more treatments becoming available.

CLL Horizons also coincided with the International Workshop on CLL (iwCLL), a scientific conference that was also held in Edinburgh. Charlotte also presented at this meeting, showing a poster of our research outlining patient preferences on the characteristics of new treatments. The aim of this was to influence those developing treatments and trials, with the hope that patient views will be considered more often.

The team are next heading to the annual meeting of the American Society of Haematology in Orlando in December, with big plans to bring you the latest information on treatments and trials. Keep an eye out for that in the next issue of Leukaemia Matters in the new year.

## Treatment updates

The treatment landscape for blood cancer patients is continuing to evolve very quickly. Here are some examples of new treatments currently being considered for use on the NHS:

- For acute myeloid leukaemia (AML) patients who are not well enough for intensive chemotherapy, glasdegib is being considered by the National Institute for Health and Care Excellence (NICE), for use on the NHS in England.
- For AML patients who have relapsed and have specific genetic mutations,



treatments being considered by NICE include gilteritinib for patients with an FLT3-ITD mutation, and ivosidenib for patients with an IDH1 mutation.

- Acalabrutinib is being considered by NICE for patients with CLL. This is a treatment that works in the same way as ibrutinib, which was revolutionary in the treatment of CLL, with the hope it will be more effective and have fewer side effects than the original ibrutinib.
- Taxograsfusp is being considered by NICE for Blastic Plasmacytoid Dendritic Cell Neoplasm. This is a very rare set of cancers affecting a type of white blood cell known as dendritic cells, and taxograsfusp will be the first approved treatment, if successful.

To keep up to date about which treatments are approved, check out the news pages on our

website. If you need information about accessing different treatment options, get in touch with the Advocacy team at the details below.

#### GP workshops a success

Nearly one-third of people with a blood cancer saw their GP three or more times before referral and diagnosis. Through workshops and e-learning, we're working to empower GPs and help them spot the signs of blood cancer sooner.

The Royal College of General Practitioners (RCGP) and Leukaemia Care held three regional workshops for GPs during 2019.

The first was for GPs from London and the South of England; the second for those in Central and East of England; and the third for those in North Wales. There were no empty seats as workshop participants discussed challenges and worked together to improve early diagnosis and referral rates.

Following the success of these events, we have extended locations during 2020 to include the North East of England and Wales regional faculties.

#### Keep in touch!

For further information about anything mentioned in Campaigns Corner, you can contact the Advocacy team by calling our helpline on **08088 010 444** or emailing [advocacy@leukaemiacare.org.uk](mailto:advocacy@leukaemiacare.org.uk). We are particularly keen to hear from:

- Patients interested in participating in our Patient Advisory Panels, which meet every six months to provide feedback on Leukaemia Care's work.
- Patients or family/friends interested in sharing their experience of blood cancer treatment, particularly those with experience of any of the treatments listed in the previous update section.

# Daily Telegraph chooses Leukaemia Care for their Christmas charity appeal

The national newspaper carefully selects three charities every Christmas and Leukaemia Care has been chosen alongside The Silver Line and Wooden Spoon.

After a staff vote, Leukaemia Care were asked to present to executives at the newspaper and in September received the news that they would be one of three charities for the 2019 appeal.

The campaign was officially launched on November 2nd and will run through until January. The focus of Leukaemia Care's appeal will be sharing stories

and experiences from those who have been affected by leukaemia.

On 1st December, the Telegraph hosted their annual phone-in day where their readers were able to make a donation over the phone. Telegraph journalists and celebrities took it in turns to man the phone lines. In 2018, 900 callers donated £85,000.

Peter Mondon, Leukaemia Care CEO, said, "We're delighted that we've been chosen by the Telegraph as one of their charities for their famous annual appeal. We're particularly

proud to be able to use this platform to highlight real stories from those who have experienced leukaemia, or are living with leukaemia, to raise awareness that leukaemia is a complicated blood cancer type.

"Being a part of this appeal has rounded off an exciting year for the charity as we mark 50 years of supporting people."

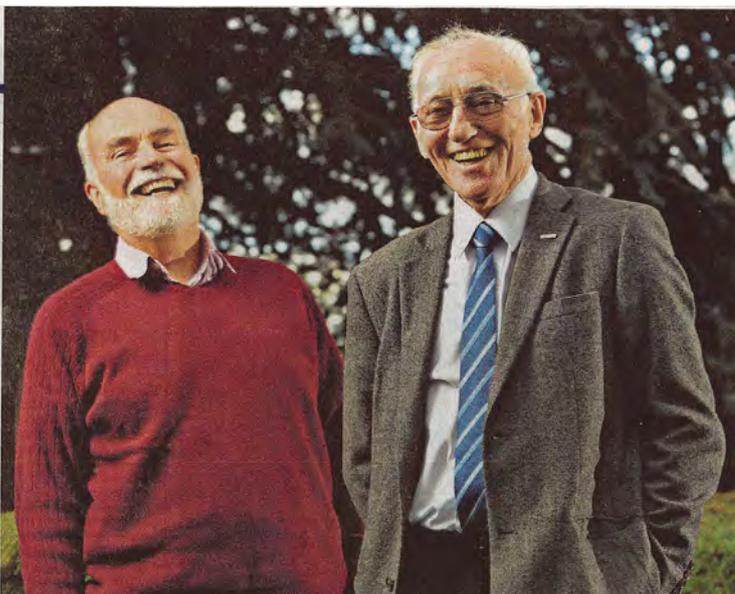
In 2018, the Christmas appeal raised over £460,000 for Young Minds, Changing Faces and the Firefighters charity.

'As long as we're still here, we'll keep talking'

*Leukaemia Care's buddy scheme allows sufferers to trade stories – and share challenges. Tom Ough reports*



he phone rang, Ian were similar ages" Hayley knew who it – Hayley is now



'Sometimes you don't talk to your family in the same way you talk to somebody who's a pal'

cold sores in 2012, he had a blood test. A few days later, he had a phone call from the hospital asking him to come in to see the oncologist. Hayley took his daughter Fiona, a nurse, with him. The oncologist broke the news. "As soon as he mentioned the C-word," says Hayley, "I just zoned out."

"Horrid, horrid time," says Price, shaking his head.

Hayley has retired too. Like Price, he has had to live a quieter, healthier life. The buddy phone calls have helped him become used to his condition, and the long-distance companionship has culminated in real-world meetings. Our meeting today, at the Principal Hotel in York, is not their first.

"It sounds very romantic," jokes Price. "We met over a bacon sandwich in Sheffield." They hadn't seen pictures of each other, Hayley says, but "I had an idea in my mind – there was a gentle-



"Thanks to Annette,  
I could be there  
at my daughter's  
wedding."

Nicky Turkoz, The  
Telegraph Magazine, 9  
November 2019

Turn over for Nicky's  
story.

# Nicky Turkoz: A friend for life

Nicky had not long turned 50 when she was suddenly diagnosed with acute myeloid leukaemia. However, thanks to the selflessness of her donor, Nicky is now nearly five years in remission. Here, she shares her story, and gives thanks to her donor and now lifelong friend, Annette.

I was diagnosed in December 2014 with acute myeloid leukaemia (AML). To say that the bottom of my world fell out that day is a major understatement.

I had recently celebrated my 50th birthday - and apart from feeling extremely tired, a couple of gum infections, and a very strange pounding in my head - I had no idea that anything that serious was wrong with me.

In September 2014, I started to have what I called a pulsating in my neck - like I could hear my pulse in my head. My doctor thought it may be tinnitus and referred me to the ear, nose and throat clinic. I received an appointment through for December 2014. In the meanwhile, I had two gum infections and was becoming increasingly tired. Everything was an effort - walking to the shops, attempting my gym classes; everyday life was more difficult. I also had a few minor nosebleeds, and my vision was affected. I was on holiday at the time, but when I closed my eyes it was like I could still see the dark outline of the sun. I subsequently learnt that this was a bleed behind the eye due to the leukaemia.

After visiting my doctor on 9th December 2014 with my general feeling of malaise, a blood test was deemed necessary.

Fortunately for me, there was a cancellation early the following morning at 9.10am.

I had my blood test, then went to work. Later that afternoon I was at home getting the Christmas tree down from the loft with my daughter when my mobile rang (4.30pm) - I left it. The house phone rang - I ignored that - I wanted to sort the tree out! Then again, my mobile rang, and my daughter made me answer it. It was my GP, and he said that he had a call from Bournemouth Hospital; they had my blood test results, I needed to go in immediately, and to take an overnight bag as I would be admitted for several days as I was anaemic.



*After the obligatory two years of anonymity with my donor, we finally met in September 2017 and we have become firm friends - she is my lifesaver!*



We were in the hospital by 6.00pm - more bloods taken and discussions with the consultant - to be finally given the devastating news that I had

acute myeloid leukaemia (AML) by 9.00pm. Chemotherapy was to begin as soon as all the tests had been completed to make sure I was strong enough to cope.

Nobody can prepare you for the journey that you are about to embark on! From the side effects of the chemo, the bone marrow biopsies, having your Hickman line inserted and removed (three times in total for me), a PICC line, and the total isolation, loneliness, despair and helplessness of the situation.

I am a single mother to two beautiful daughters who were 19 and 22 at the time of my diagnosis - the impact on them was massive. My youngest daughter was living and working abroad at the time and gave up her job to come home and help look after me alongside her sister. It was a total role reversal - naturally as a mother you do the parenting - but I was unable to do so anymore, and that was very hard for all three of us. Such a difficult, demanding, emotional and uncertain time.

Sadly, I was diagnosed as being of high risk of relapse, so I would need a stem cell transplant. This took place in Southampton Hospital on May 20th 2015 - my new re-birthday. I received my new stem cells at approximately 6.30pm - my day zero, and my

With thanks to Ben Cotterill of [www.bencotterillphotography.com](http://www.bencotterillphotography.com) for the photography





PICTURE: ANNETTE (LEFT) DONATED HER STEM CELLS TO SAVE NICKY'S LIFE.

chance of survival.

I spent a total of 19 weeks and four days in hospital receiving treatment. I was euphoric at being discharged, home to my bed and familiar surroundings. Yet this was just the next important phase of my recovery.

Initially I had two appointments per week for the first month, then once a week and then once a fortnight, slowly diminishing the longer I got from my transplant. I am now on once every three months.

In the first 18 months post-transplant, life as I knew it was very much on hold. I was unable to mix with people, no shopping, no going out, as I had no immune system and normal coughs and colds could become life threatening for me.

Yet more isolation.

My hair began to grow back, and slowly my appetite began to return. I started to look and feel like my old self again, slowly resuming my life, albeit now with a totally different perspective.

Throughout the period after my stem cell transplant, my daughters and I regularly wrote to my donor, thanking them for saving my life. After the obligatory two years of anonymity with my donor, we finally met in September 2017 and we have become firm friends - she is my lifesaver!

The most special thing is that Annette, my donor, was a guest of honour at my daughter's wedding last May (2018) and I was lucky enough to give my daughter away - a very special moment considering all that we had been through.

Annette and I have such a special bond; we message each other every day and we try to visit each other once a month despite living 150 miles apart. We are genetic twins.

I will be five years post-transplant on 20th May 2020. It is most certainly a very special day for us, as if it wasn't for Annette, the fabulous doctors and nurses, I probably wouldn't be alive to celebrate today.

Could you save someone's life?

To join the stem cell register, head to:

- DKMS - [www.dkms.org.uk/en](http://www.dkms.org.uk/en)
- Anthony Nolan - [www.anthonynolan.org](http://www.anthonynolan.org)

# Changes in appearance

In this article, our Nurse Advisor, Fiona Heath, is taking a look at how a blood cancer diagnosis can affect your appearance. Read on for her tips and advice.

There can be many changes in appearance when you are going through your blood cancer journey, from diagnosis to treatment and beyond, and it can be especially difficult to deal with these changes around a time such as Christmas.

Different treatments may have a different effect on your appearance. Chemotherapy is the most common cause of changes to hair, skin and nails. Other treatments that may also have an effect on your appearance include hormonal therapy, some targeted therapies and radiotherapy.

## Hair loss

Body hairs including the scalp, eyelashes, armpits, and pubic hair can fall out. Hair loss occurs because some chemotherapy drugs may affect actively dividing cells, including cancer cells and hair follicles. Hair loss may begin a few days to weeks after starting treatment but is usually temporary, and normally reverses on completion of treatment. Some people who receive low dose chemotherapy may experience thinning of the hair but not total hair loss. Hair may start to grow back before treatment is completed or even grow back and fall out

again during different phases of your chemotherapy. Following treatment, hair may also grow back differently to how it was before, including in texture or colour.

Our hair can be an important part of our appearance and identity. It may be a way we express our personality. Often, when our hair looks good, we feel good. As a result, many people find losing their hair upsetting. You may feel uncomfortable about socialising with your different appearance. If your hair is important to you for religious or cultural reasons, it can be even more difficult to adjust to losing



it. You might also worry about how it will affect relationships with your family and friends.

Some people describe hair loss as one of the most distressing physical and psychological side effects of cancer treatment, and the value of hair loss cannot be underestimated.

There are many practical ways to cope with hair loss. They do not make the problem disappear, but they can make life a bit easier for you during this difficult time. The NHS has a provision for wig supply for those who may need them. There are several options for wigs, which include human hair wigs or synthetic wigs. For more information, see: [www.nhs.uk/NHSEngland/Healthcosts/Pages/Wigsandfabricsupports.aspx](http://www.nhs.uk/NHSEngland/Healthcosts/Pages/Wigsandfabricsupports.aspx)

There are also wigs and headwear options available for children. The Teenage Cancer Trust provides young people with a free, human hair wig.

Alternatively, you may choose to shave off your hair before it starts to fall out, or you may choose to wear head scarves, hats or nothing at all. Look Good Feel Better is a charity that can help you with this. You can find out more information on their website at <https://lookgoodfeelbetter.org>

Most people find that their family and friends are very supportive, and that it can help to talk through your feelings about losing your hair, but it may take some time for you to come to terms with your hair loss. It may also take you time to talk with other people about your hair loss and deal with their reactions.

### Skin and nail changes

Chemotherapy may affect your skin, fingernails and toenails. Skin toxicity from chemotherapy can cause skin sensitivity, with symptoms of itchiness, dryness,

rash or hyperpigmentation which can make people more vulnerable to sun burn.

Changes to fingernails and toenails are also common during chemotherapy. Toenails and fingernails may become brittle, change colour, crack or cause partial breakages from the nail bed.

There are some ways to help maintain good skin and nail care. Skin care is important during and after treatment. Some useful tips include:

- Use skin moisturisers or emollients, as well as cuticle cream
- Avoid alcohol based and perfumed products which may dry the skin
- Protect yourself from sunlight
- Apply skin protection creams and cover up when going in the sun
- Use gloves when washing dishes

### Weight loss

It is usual for you to experience variation in your weight and there are several factors that can contribute to this during treatment. These include weight loss caused by gastrointestinal symptoms of nausea, vomiting or diarrhoea, or treatment-related mucositis (sore mouth) and loss of appetite.

Changes in taste sensations can also affect the ability to maintain weight during treatment. These are all factors that can result in eating less and affect your weight. Also, patients may be given steroids as part of their treatment for some blood cancers, which may cause them to gain weight. Steroids can also make your skin more prone to spots and reddening.

Anybody starting chemotherapy

treatment for leukaemia is weighed. Baseline weight is important because it helps to calculate baseline body mass index (BMI) and because, traditionally, intravenous chemotherapy dosages are based according to your body surface area (BSA) or body mass index (BMI). If you experience extreme weight loss it is important that you speak to a specialist dietician. Dietary advice also plays an important part in maintaining a good weight.

Changes in appearance can have a significant effect on how you feel about yourself. Many people find that knowing about possible changes in advance helps them deal with them later on, so it's important to talk to your doctor or clinical nurse specialist before you have treatment. Some people find talking to other people who have been through something similar reassuring, but it isn't helpful for everyone. It is important to give yourself time to adjust to changes to how you look. Don't feel that you have to explain to people if you do not want to, but do seek support from the people you feel will be able to help you.

Some of this information was taken from our 'Living Well' booklets:

- Living Well with Acute Lymphoblastic Leukaemia (ALL)
- Living Well with Acute Myeloid Leukaemia (AML)
- Living Well with Chronic Myeloid Leukaemia (CML)
- Living Well with Chronic Lymphocytic Leukaemia (CLL)

Download or order these booklets for free by going to: <http://bit.ly/LCBooklets>



# Fundraisers go all out for our 50th year

Our fundraisers mean the world to us, as they enable us to continue to support all those affected by blood cancer. Here, we take a look at just a few of those very special people who did their bit for blood cancer patients in 2019.

## Jacques family get quizzical

Laura Jacques and her family have spent much of 2019 organising a number of exciting events for Leukaemia Care, including a successful quiz night that raised an astonishing £2,708.14!

Having set themselves a target of £5,000, they've nearly reached their goal in less than a year, and have also helped to raise awareness of leukaemia and its symptoms by getting involved in our September #SpotLeukaemia campaign.

## London Marathon runners go bigger than ever

For 2019's race, our team of London Marathon runners raised a whopping £454,316!

Two runners that helped to make the 2019 race such a success were brothers Ben and Ed Bowler, who raised a staggering £15,023.70 between them.

## Supermarket star

Fantastic fundraiser Tony Wright has been hard at work organising supermarket collections for Leukaemia Care,

often collecting donations and talking to people for seven to eight hours!

Claire Merritt, Community Fundraising Officer for Leukaemia Care, said, "He has done fantastically this year; his work/volunteer ethic and dedication to doing the collections for us is just incredible—we are so grateful to him for his hard work. Since November 2018, Tony has raised £1,686 for us from supermarket collections."

## Dharmesh takes to the skies

Earlier this year, fundraiser Dharmesh Mehta took on a skydive for Leukaemia Care, raising an amazing £1,678.16.

Dharmesh himself was diagnosed with chronic myeloid leukaemia (CML) despite not experiencing any symptoms. Dharmesh is now doing well, and along with taking on a skydive, he also shared his story for our #SpotLeukaemia campaign, which you can read on our website at: <http://bit.ly/DharmeshMehta>.

## School goes spotty for beloved teacher

After teacher Sarah Paling was diagnosed with acute myeloid leukaemia (AML), her school, Crackley Bank Primary School, decided to get stuck into fundraising to show their support.

Now in remission, Sarah has been supporting the pupils in their latest fundraising event where they went spotty for us as part of our #SpotLeukaemia campaign. The school have raised a brilliant £2,148.73 to date.

Sarah also shared her story for #SpotLeukaemia, which you can read here: <http://bit.ly/SarahPaling>.

## Team Sofa to Saddle conquer RideLondon

At this year's Prudential RideLondon, one brave team took on the 100-mile cycling race in aid of blood cancer patients.

Team Sofa to Saddle, comprised of 21 novice riders, put their all into both their training and fundraising, raising an amazing £10,677.05!

PICTURE (RIGHT): THESE 'BOB THE BLOOD DROPS' HAVE BEEN CROCHETED BY SUPPORTER CAROLYN WHITTAKER



PICTURE (ABOVE): TEAM SOFA TO SADDLE TAKE ON PRUDENTIAL RIDELONDON

### A special mention

We'd also like to mention one hard-working fundraiser who has dedicated a large amount of her time to supporting Leukaemia Care in 2019.

Carolyn Whittaker sadly lost her husband Roger in 2014 after he was diagnosed with AML. In memory of Roger, Carolyn has been crocheting our

hugely popular 'Bob the Blood Drops', which have sold out numerous times on our eBay shop this year. She has also hosted collections in her local supermarket and has so far raised over £1,100.

A huge thank you to everyone who fundraised for Leukaemia Care in 2019.

Could you do the same in 2020? Get in touch with our Fundraising team by emailing [fundraising@leukaemiacare.org.uk](mailto:fundraising@leukaemiacare.org.uk) to receive your free fundraising pack.



# Thea Wilson: A story of survival

Thea Wilson was diagnosed with acute promyelocytic leukaemia (APL/APML) in December 2014. Five years on, Thea reflects on her treatment and shares her thoughts on survivorship.

## Survival

The state or fact of continuing to live or exist, typically in spite of an accident, ordeal, or difficult circumstances.

## Patient

One who suffers.

Over 1,700 days.

114 days of drugs.

16 chemotherapy transfusions.

8 blood transfusions.

70 platelet transfusions.

20 frozen plasma transfusions.

30 fibrinogen transfusions.

576 ATRA tablets.

23 bone marrow aspirates.

700 days of waiting for results.

What does that do to a person?

## 2014

2014 was busy. International dating, finally getting good at running up mountains, bought my forever beautiful horse Billy. A new role within my company was on the horizon taking me out of my comfort zone, pulling on my brave pants and pushing me into a career I had always dreamed of, finally an opportunity to make a difference.

## October/November

International dating was getting tiring, running up hills was getting really tough and my body was doing some crazy stuff! Bruises started appearing, I started to pee blood, I'd wake up with infections in various body parts, my mouth was full of blood blisters... but with the reassurance from my GP that a dose of steroids would fix me, I continued to travel and run, and thought it was a great time to start jumping my horse. I look back on those days now with complete fear—what if?

The answer is always the same... I would not be here now.

## December

"I am so sorry Thea, it is cancer."

What do you do with that? Repeat the apology to those sitting in that small room with you and look at their faces, destroyed by the news that a daughter and a friend has just been told she has a disease that could take her away from them. I still don't really recall the thought processes I went through other than I needed new pyjamas.

How was I going to tell my employers I wasn't going to be at work on Monday and oh also a high probability that I may never return to work? In fact, I might

die... no I won't die, I just might, might is better than will.

I look back on the calls I had to make, the hardest thing I've ever had to do to other people – telling those that you care and love you have cancer, knowing you are responsible for the impact that this will have on them.

My practice call was to an ex-boyfriend. He was a positive, fun guy who would know what to say to me. He was about to get on a plane. He did get on that plane because I told him to go away, then when he came back, he could then visit me to tell me funny stories about falling off mopeds. I knew but didn't share that I might not be there to hear the stories.

I kept that to myself and smiled every time someone said, "You are a fighter, of course you will get through this."

## APML

Is now the most curable type of leukaemia; because of medical intervention and treatment protocols, 70-80% of patients survive this disease if treatment is delivered early. Historically, this type of leukaemia had a 0% chance of survival because bleeding could not be controlled.

The challenges facing me: extremely late presentation.



My bone marrow had been taken over by cancer cells that didn't allow me to clot. I was spontaneously bleeding with only one outcome if my body continued to fail.

Enter the conflict zone: PML RARA v Platelets.

Spoiler alert - I survived.

I became patient number 958833; I am still patient number 958833. I wonder if the number 958833 will ever become something I can't quite remember.

My focus was on surviving. I couldn't and wouldn't lose sight of this. Adapting to a new life and becoming fluent in a new language. Coming face to face with my own premature mortality, only saved by a cocktail of toxic drugs, transfusions and life-saving blood products.

How do you come to terms with that? An unfulfilled life because

cancer had the potential to dictate the outcome.

Room 5 on Ward 23, Royal Shrewsbury Hospital, my new home indefinitely. Enveloped, protected, medicated and cared for, sent well wishes from friends, family and distant once upon a times. In response, I took it all in, absorbed it, never processed it but always responded in a usual TW way. The power of a smile.

### Hitting the Master Reset button

Being shut down and re-booted four times over a six-month period became the new normal. During this time, I just existed. Nothing prepares you for the post chemo days, my inner voice working so hard to keep me focussed and positive. "Dig deep, you can do this, this time in a few days your mouth won't hurt so much, by the end of the week your white cell count may have raised above 0, next week you may even be able to reduce the

transfusions. Next month you might be able to go home."

The lines I was attached to giving me the blood support I desperately needed, but as quickly as it was going in, the leukaemia ravaging my body was destroying it.

The treatment wasn't working - I really wish they would train SpR's (specialist registrars) to deliver news better. I expressed concerns that I was worried I wasn't responding to treatment; I remember his response well - "Yes, we are too." A trained professional should have recognised that as a chink in my armour and asked me if I needed some support. Nope, he shuffled off and left me sat in my bed watching my PICC line delivering a fibrinogen transfusion and some s\*\*\* breakfast TV wondering, *what is the point?* I have had enough. Stage right, enter Julie, my brilliant lady dressed in pink asking if I wanted a cup of tea;

she was part of the army of amazing humans that made me feel normal.

Fight, be tough, keep strong, don't give up. All words written in the cards that adorned my walls. There wasn't room for self-pity and why me's. I had to smile, there were too many people counting on me to get them through my disease.

Christmas came and went, New Year's Day saw me take my first steps out of my room, down 32 steps and out into the big wide world. The big wide world has people coughing in it, runny noses, dirt, infectious people, animals. I panicked and wanted to go back up the 32 steps to my room, safe. I stayed out of my protective bubble for a few hours—the day I had been so looking forward to was such an effort mentally.

A few weeks later I packed my new home into boxes and headed to my mum's house. This was easier. My friend turned over the ignition, the radio kicked in. I heard the words, "Girl you're amazing." Thanks, Bruno Mars, for recognising my special day and singing your song just for me.

The next few months I was treated in and out of hospital depending on where I was in my chemo cycles. Respite was at mum's. The third was the worst - blue stuff, this one hit me hard and put me back in hospital. I felt destroyed and wanted to give up. Trying to hold on to one day I would get to go home, proper home.

### Home time

Walking through the door was emotional—I had made it. Survived the cancer and survived the treatment. My chalk board read, "Welcome home TW".

I felt exhausted, worn out, ached all over, I was sweating toxic waste, my hair had gone but I

was home. This was the first time I took a good look at myself in a mirror. I wasn't there. It was the first time I sat down and wrote something.

Looking forward to this being done  
I've got to say it's not been fun

Thoughts and fears swirl in my head  
Missing my shed and my comfy bed

For now I comply to my doctor's rules  
I tell you now Cancer you are the fool

I will beat you, I will tell my tale  
I've always believed my body wouldn't fail

Poke me and prod me, stike a line in my arm  
I will smile and be happy, my inside remains calm

I look in the mirror, I see a pale face  
An image I sometimes struggle to place

My eyes are tired, my hair on its way out  
How did this happen? What's it about?

The treatment almost complete  
The doctors now say I have this thing beat

I know now the end is in sight  
I will bask in that glorious light

The light of success, the victory mine  
No listen, Cancer, it's my time to shine

The hardest part was yet to come.

### Re-entry and re-identification

My total focus had been on surviving, then all of a sudden, I had achieved it. What now? Overnight my inner scaffolding taken down, no healthcare army, no medication, no routine, nothing! Just quiet and I was alone. I actually found myself fantasising about being sick again. I had been released back into normal society where I was normal, not qualifying as a sick person anymore.

### The Invisible Battle

This is where the real challenges of recovery become a struggle. It is a privilege that many don't get to experience.

- Fear
- Relapse
- PTSD
- Side effects
- Long-term side effects
- Isolation
- Misunderstood
- Grief
- Sadness
- Fatigue
- Frustration
- Anxiety

I turned 42 in July. At the age of 37 years 4 months 21 days, the reality of the life I had imagined was lost after hearing one sentence.

In February 2020, I hope to hear the words cured. Being cured is where the healing begins.



# Taking part in a Research Study: What do I need to know?

Our Nurse Advisor, Angela, has years of experience in clinical trials. Here, she looks at what you need to know before joining a clinical trial.

Patients who have a diagnosis of leukaemia may be asked to consider taking part in a national clinical trial/research study, if this is available, as part of the treatment options being put forward by their specialist teams.

Before a decision is made to take part in the research study, it is important that each patient is able to have an understanding of why the research is being done and what it will involve. An explanation about the proposed study is given by the specialist team to the patient.

An information sheet is also provided for each person to read and to discuss with others and their family if they wish. There will be time to decide if you wish to take part and ask any questions that you may have for your doctor. In order to proceed within the study, written consent is required prior to any trial procedures taking place.

The information sheet will consist of a few pages which are split into sections relevant to each study. When reading the information about the particular study, the following

points are important to consider.



## What does the study involve and what does it mean for me?

This section of the information will give details about which treatments are being compared with each other if this is a study about chemotherapy/ immunotherapy treatments. Each person will need to have an idea of the type of therapy and how it will be given; for example, if this is as a drip, tablet or in a liquid form. It is important to have an idea of how long the treatments will last on each occasion and how they are meant to be administered.

If the treatments are to be taken as a tablet or as an injection under the skin surface, the patient and their family may need to consider who would be able to support them with their medicines in their home environment.

Information relating to each course of treatment will be provided in this section. This includes how many courses of therapy, side effects that may occur, and how many likely hospital visits are required. Further information about blood tests that will be needed



during the study, and follow up questions about quality of life, will also be discussed if these are part of the research study.

There will be an overview of each of the treatments being compared with the study, with a description of each therapy and its potential benefits and risks, in more detail so that patients can be well informed of their options available.

#### **What if new information becomes available during the trial?**

It is important that patients are aware that sometimes during the course of a trial, new information becomes available about the treatment or the drug that is being studied.

This new information will be discussed with you by your specialist team if this will affect the way that your treatment might be given or changed in any way. It may be that a further consent form will be needed if treatments are being switched.

On occasion, but rarely, a study might be stopped earlier than

planned. This is very unusual and is why independent monitoring committees are involved with a study's progress. Some treatments within the study may not be available at all times for different reasons. If this occurs, the research team will provide an explanation and further details for each patient involved in the study.

#### **Who is organising, and funding the research?**

Each study is supported by a sponsor who provides the overall responsibility and ensures the proper conduct of the trial. The sponsor—usually a university—will have many years of experience of running trials in leukaemia.

The studies are organised by the National Cancer Research Institute (NCRI) and the daily administration of the study is managed by a clinical trial team within the university's research centre. Each study is continually and carefully monitored throughout the trial from the start of the study to closure.

The leukaemia research studies

are scientifically reviewed and approved by a national committee representing the Medical Research Council and Cancer Research UK. A study receives its authorisation from the Medicines and Healthcare Products Regulatory Agency (MHRA), and National Ethics Committee. Each hospital taking part in a research study has to have approval to from their trust's Research and Development office before it can commence.

The information sheet will also include these national organisers' contact details and the local Lead Consultant that is responsible for the running of the research study at their hospital trust.

#### **Websites for further information:**

Medicines & Healthcare Products Regulatory Agency

MHRA - <https://www.gov.uk>

National Institute for Health Research

NIHR - <https://www.nihr.ac.uk>



**Merry  
Christmas from  
everyone at  
Leukaemia Care**