Leukaemia Matters

Spring edition 2024

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Our free quarterly patient magazine

www.leukaemiacare.org.uk

Leukaemia Care
YOUR Blood Cancer Charity

In This Issue

Patient stories:

Plus:

Hello,

Welcome to our Spring edition of Leukaemia Matters!

We extend a warm welcome to Colin Dyer our new CEO who joins us from the Special Olympics GB charity.

In this edition, alongside Colin's CEO report, we feature Mark's story as he celebrates 20 years since his diagnosis by running the London Marathon, which will also be his 16th marathon, and his third in the capital.

On a sporting note, we hear from Nicholas who has competed in the World Transplant Games and works hard to raise awareness of transplant patients competing in the sporting arenas.

Also, looking at the vital services we provide we meet 90-year-old Olga who is a strong advocate of our Buddy Scheme where, despite a nearly 50-year age gap, she and buddy Anna have formed a great friendship.

Free Wills Month has drawn to a close, but you don't have to wait until October, or next March, to take up this service. At the end of this issue, Doreen tells us her story and why she made a pledge to Leukaemia Care in her Will.

As with every year, our work as a charity is only made possible by your support, contributions, and donations. Thank you for continuing to support Leukaemia Care in 2024.

Remember, it is more than okay to reach out if you need support. Call us on our FREE helpline on **08088 010 444**, email us at support@leukaemiacare.org.uk or message us on WhatsApp at **07500 068065**.

If you're reading this issue in a hospital or GP surgery, you can sign up to receive your own free copy of Leukaemia Matters magazine. Just call **01905 755977** or visit our shop here.

We wish you a wonderful spring time.

Chris Matthews-Maxwell
Chairman

CEO Report: Moving forward in 2024

Firstly, I'd like to say a heartfelt thank you for the very warm welcome I have had from those people connected to Leukaemia Care that I have already had the chance to meet. It is already clear that there is a strong sense of community, empathy, and determination both within the core charity team and throughout our wider network.

Those values came through incredibly strongly in the recent Leukaemia Care BBC Lifeline Appeal, hosted so passionately by Dame Arlene Phillips. The reaction to that video has been nothing but positive, and I am delighted that we have already seen donations almost reach £15,000 with more to come I am sure.

The messages contained in that video clearly resonated with so many people, and demonstrated very clearly exactly what this charity is all about. As John, who featured in the appeal, so perfectly put it when describing Leukaemia Care: "they understood, they got it!" and there can be few better testimonials that that.

In the past 20 years or more, leading and working alongside beneficiary-led organisations with a similar ethos and mission to Leukaemia Care, I have seen first-hand the incredibly positive impact that innovative support, targeted where it is most needed, can have. And that matters not just when it comes to essential work for patients, but also for family, friends and carers.

The focus for us all moving forward will continue to be the development of those Leukaemia Care information, advice and support projects and services that have the biggest impact for people when they need it most. And we will continue to work to spread the word as far and wide as possible to ensure that everyone who needs us has the chance to connect and benefit.

I'm now looking forward to continuing to meet as many people as possible, and taking the opportunity to understand and listen to those that know best about how we can continue to increase our impact in the years to come. And, of course, please do reach out if you feel you can help us in any way.

Warmest wishes,

Colin Dyer
CEO at Leukaemia Care

We exist to improve the lives of everyone affected by leukaemia, myelodysplastic syndrome (MDS) and myeloproliferative neoplasms (MPNs).

We raise awareness of the issues impacting people affected by leukaemia, MDS and MPN, and campaign to fix them.

We bring people together and unite them behind our common goal. Together, we will create the future we all believe in.

Find out more on how to volunteer and get involved **here**.

Leukaemia Care
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Research updates

Amongst the numerous studies presented at 2023's American Society of Haematology (ASH) conference, we have picked out interesting updates that you should know about.

Updates for acute myeloid leukaemia (AML)

Quizartinib

A potential new treatment for AML, quizartinib, is currently being assessed by The National Institute for Health and Care Excellence (NICE). NICE is looking at the evidence to decide whether quizartinib should be available on the NHS in England. (Wales and Northern Ireland usually follow NICE guidance. Scotland has a separate system for assessing medicines.)

What is already known about quizartinib?

Quizartinib is a targeted treatment that you take as an oral tablet once a day. It blocks a protein called FLT3, which is involved in cell growth and division. Quizartinib specifically blocks a version of the FLT3 protein made by a gene that has a change called a FLT3 ITD mutation. This mutation can make AML difficult to treat.

In a trial called QuANTUM-First, 539 adults with newly-diagnosed AML and a FLT3 ITD mutation were randomly allocated to be treated with either:

- Standard chemotherapy plus quizartinib for induction and consolidation, followed by up to three years of quizartinib alone for maintenance
- Standard chemotherapy plus dummy treatment (placebo) for induction and consolidation, followed by up to three years of placebo alone for maintenance.

This was published late last year. The study found that adding quizartinib to standard chemotherapy, followed by quizartinib alone for up to three years, improved overall survival in patients with newly-diagnosed AML and a FLT3 ITD mutation.

Average overall survival was 31·9 months for patients who had quizartinib compared with 15·1 months for patients who had placebo. Also, average length of complete remission was longer in patients who had quizartinib than those who had placebo (38·6 months compared to 12·4 months).

The rate of side effects was similar in both treatment groups, but patients taking quizartinib had a higher rate of serious side effects. These were managed through monitoring and dose reductions.

NICE takes into account both the clinical effectiveness and the cost of the treatment when it decides whether or not to approve the treatment. We will report the results of the process which are expected in October.

Updates for chronic myeloid leukaemia (CML)

Potential new option for patients who have tried several current treatments

Tyrosine kinase inhibitors (TKIs) are generally very effective in treating CML. However, some people have CML that does not respond, or stops responding, to currently available TKIs. Others have side effects that mean they have to stop treatment.

A recent study, presented at the ASH conference at the end of 2023, has looked at a treatment called olverembatinib for treating chronic phase CML in people who have already had several TKIs. Olverembatinib is a new third-generation TKI that you take by mouth every other day.

In this study in China, 144 adults with chronic phase CML who had previously been treated with three or more TKIs were randomly allocated to either:

- Olverembatinib
- Best available therapy (BAT) - either a different TKI (imatinib, dasatinib or nilotinib), interferon, hydroxyurea or homoharringtonine.

The trial found that olverembatinib was more effective than BAT.

More patients in the olveramatinib group than the BAT group achieved a major molecular response (27.3% compared to 8.1%).

This early Phase 2 study suggests that olverembatinib could be a promising treatment option for patients who have failed multiple TKIs. It will need further testing in larger clinical trials.

Updates for acute lymphoblastic leukaemia (ALL)

Kinder cancer treatments

A treatment for ALL hit the headlines in January, thanks to the option for patients to have it with them wherever they go. Here we answer some questions you might have about this treatment:

What is it?

Blinatumomab is a treatment that is known as a bi-specific antibody (BiTE). It works by attaching the leukaemia cells to a toxin that kills them, using an antibody as a bridge. It attaches to a protein specific to the ALL cells, so it's less likely to cause side effects by attacking the non-cancer cells.

Isn't it already available?

Yes. Adults with certain types of ALL can already be prescribed blinatumomab. The news story was highlighting a need for children to also get access.

What's the benefit of this treatment compared to the usual treatment?

The haematologists in the piece believed that blinatumomab has fewer side effects on average. The piece also showed that patients can have it from home. The patient had it in his own bed, which he and his parents talk about being really important for his quality of life. However, it's known that chemotherapy can put people in remission long term, whereas blinatumomab is too new to know that for sure. Also, blinatumomab does have side effects, so it may not be for everyone. It's important to discuss all options with your doctor.

Leukaemia Care supports the call for blinatumomab to be considered, through the usual processes, as a routine option for children.

Want to understand your treatment options? Contact us on the helpline **08088 010 444** or email support@leukaemiacare.org.uk for help from our support team.

How to choose between transplantation and CAR-T? A debate goes on

Arguably the biggest change in treating ALL lately was the approval of CAR-T treatment on the NHS.

However, for many decades, stem cell transplantation (SCT) has also been available. There are pros and cons to each treatment, and different information available. This leaves doctors and patients with a debate; which is best for who? At the recent meeting of the ASH conference, various doctors across America tried to answer this question. Dr Shah from the US National Institute of Health said that individual patient factors, like previous complications and donor availability, are more important in the decision than what is best for the hospital.

Dr Bertaina of Stanford University argued that working out the best order of treatment for maximum impact is more important. She said that more research into the biology of leukaemia cells might provide "markers" of certain groups of patients who would benefit from one treatment over another.

Finally, Dr Gossek of St Jude's hospital in Tennessee pointed out that there remain some patients who do not benefit from either treatment and we still need more options after CAR-T. Overall, the session offered hope that we may find answers in the future, even if choices are not clear cut at present.

Updates for chronic lymphocytic leukaemia (CLL)

An update to the FLAIR trial

Research presented at the ASH conference in December last year mainly focused on learning more about the treatments we already have access to in the UK for the treatment of CLL.

Many CLL patients diagnosed around 5 to 10 years ago will be familiar with the FLAIR trial. This was a trial that originally aimed to explore whether ibrutinib with rituximab was a more effective combination of treatment than FCR (chemotherapy made up of fludarabine, cyclosphosphamide and rituximab). It has, in more recent times, looked at other combinations of ibrutinib compared to FCR.

At the most recent annual meeting of ASH, Professor Hillmen from the UK presented the latest trial data comparing ibrutinib with venetoclax (I+V) with FCR. Both are treatments currently available, but it is useful to clinicians to continue to explore which treatments are best. There are several options available to most CLL patients now, so the order of treatments becomes important.

Professor Hillmen and the team concluded that I+V improves progression free survival compared to FCR. At three years, 97% of I+V patients were still progression free (i.e. their disease did not get worse in that time), compared with 77% of patients who had FCR.

Importantly, the research team also showed that you can measure the level of CLL cells left in the blood (known as minimal residual disease, MRD) of patients on I+V to help guide treatment duration.

LC News

As we are a few months into the new year, here are the latest updates for 2024.

We raised over £12,000 for our Snow Much Love Appeal

Back in November 2023, we launched our Snow Much Love Appeal and we are pleased to announce that we raised an amazing £12,701! We want to say a massive thank you to every person who donated. Thanks to these vital funds being raised, we can continue to support those affected by leukaemia, MDS and MPNs.

Buddy scheme enters its sixth year

Our one-to-one buddy support service matches you with one of our trained volunteers for regular or one-off telephone calls or emails. Six years since its inception, it continues to provide support and even friendships to those who use it.

Apply for a buddy or to become one of our buddies by heading to the service page on the website **here**.

Register for ongoing updates for our online support groups

Our online support groups take part throughout the year, giving you the opportunity to meet others across the UK in a similar situation. Our groups may be created by disease type, topic or even a particular interest. They're free to join and you can register for updates on as many groups as you like.

To find the full list of online support groups, head to our website **here**.

In-Person groups continue to meet to register your interest in finding out more about face-to-face support, call **08088 010 444** or email **support@leukaemiacare.org.uk**

Smiley Charity Film Awards

We're thrilled to share that our "Why Spot Leukaemia?" video won bronze in our category at the Smiley Charity Film Awards. The video was launched in September 2023 for Blood Cancer Awareness Month as part of our Spot Leukaemia campaign with Leukaemia UK to help raise awareness of the signs and symptoms of leukaemia. It centered on urging individuals, aged 65 and above, to embrace their innate curiosity by asking 'why' more often, especially concerning any changes in their health.

Want to ensure you're always up to date with the latest news? Sign up for our e-newsletter so all the latest updates land straight in your inbox each month! Sign up **here**.

Leukaemia Matters Autumn edition 2023

Bethan Cawley: Why CLL has changed my view on life
Read more on page 14

Becki Lucas: Why my positive mindset made a difference
Read more on page 12

Our free quarterly patient magazine
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Leukaemia Care
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Become a regular giver today

We will move mountains for anyone who has been affected by a leukaemia, MDS or MPN diagnosis. But we can't do it without you. Your support ensures we can continue to provide our services to those who need it most, including this magazine. By becoming a regular giver you can contribute to the cost of creating, printing and sending out every edition of Leukaemia Matters.

If you are able to make a regular donation of any size, you can do so **here**.

Updates: Drug approvals you need to know about

The National Institute for Health and Care Excellence (NICE) and the Scottish Medicines Consortium (SMC) has kept us busy once again with plenty of announcements across the UK.

15th February

Leukaemia Care and MPN Voice join forces to successfully campaign for new myelofibrosis (MF) treatment.

We were pleased to share that NICE approved momelotinib treatment for use on the NHS in patients with MF in England. It has been specifically approved for:

- Patients whose myelofibrosis is rated as intermediate-2 or high risk **AND**
- Have an enlarged spleen **AND/OR** moderate to severe anaemia.

Momelotinib is now an extra option for patients who have never had treatment before, as well as those who have previously had ruxolitinib, allowing patients and doctors to choose the right treatment for them.

For this treatment appraisal, Leukaemia Care collaborated with the charity MPN Voice to provide evidence on patient experience and outline the case for this treatment to be approved.

Find out the details of this announcement here.

11th March

New treatment in Scotland for patients with acute myeloid leukaemia (AML) was approved.

The SMC has announced that ivosidenib with azacitidine will now be approved for use on the NHS in Scotland. It will be used to treat eligible patients with newly diagnosed acute myeloid leukaemia (AML) with an isocitrate dehydrogenase-1 (IDH1) R132 mutation who are not eligible to receive standard induction chemotherapy.

There are currently no treatments that are specifically targeted for AML patient with an IDH1 mutation. Ivosidenib with azacitidine will be the first treatment specifically for this group of patients.

This treatment is currently going through The National Institute for Health and Care Excellence's (NICE) process in England which Leukaemia Care are currently involved in. We expect NICE to make a decision in the following months.

Everything you need to know about this announcement can be found here.

Do you need support?

If you want to know more about what treatments are available for you, how treatment decisions are made or have any other question related to treatment, please contact us via our helpline **08088 010 444**, or send your question to WhatsApp on **07500 068 065**. Alternatively you can email our team at **support@leukaemiacare.org.uk**

Elizabeth Ojaba: My story

Elizabeth was diagnosed with a rare form of acute myeloid leukaemia (AML) ten years ago, to then find out she actually had a type of chronic myeloid leukaemia (CML). Here she recounts her story.

It all began with a blood test in July 2014. At the time I was 55 years old, full of life, and about to start a new job in Geneva.

On reflection, I was experiencing a series of perplexing symptoms—a painful swelling on my left wrist, prompting a blood test at my GP surgery which revealed I had elevated uric acid levels, indicating gout and rheumatic arthritis and I was prescribed medicines for this but I ended up having several allergic reactions to the treatment which led me to being referred to the Mile End hospital. A few weeks after that, I also started experiencing unexplained breathlessness during physical activities.

Two days after I got home from my job orientation in Switzerland, I went to Mile End Hospital for my blood test and review appointment. Then, 24 hours later, I received a call urging me to go to St. Bart's Hospital for further checks. On arrival, I was told to go to the haematology department. The words "Oncology and Haematology" etched on the door set me into panic mode - something was really wrong with me - could it be cancer? Having been previously diagnosed with breast cancer, it was definitely another one of those scary moments.

I sat down with the consultant who suspected that I had leukaemia, but they needed to perform a bone marrow biopsy to confirm this. I was then told that I had AML and, after further investigations, Philadelphia-chromosome positive AML (a rare subtype which affects between 15 to 90 people each year in the UK). I needed to have chemotherapy and was asked to be admitted immediately to start treatment the next day. As it was a Friday, I requested to be allowed the weekend to sort myself out and to start treatment from the Monday.

The following two months were gruelling. Constant rounds of chemotherapy left me physically and emotionally drained. The side effects were merciless – hair loss, excruciating mouth sores, constant nausea, and debilitating fatigue. The other aspect I remember with horror was when one of my teeth became infected while still struggling with neutropenia. I developed neutropenic sepsis which nearly took my life. I also experienced allergic complications to my first platelet transfusion which left my mouth, neck and face swollen for three or four days.

By this point, with lots of side effects and my neutrophils count staying at 0, I was getting fed up and asked to be discharged. On 5th September, I was finally allowed home under the agreement that I would maintain my isolation. Two days later, when I returned to hospital for a blood test and review, for the first time my blood test results returned a neutrophils count of 0.01. I was ecstatic with joy, jumping up and down and hugging the nurses. My neutrophils gradually improved but hovered mostly between 0.5 and 1.

But, when it all seemed to be going in the right direction, life threw something else in my direction. One month after my discharge, I ended up being readmitted to hospital with neutropenic fever and painful cellulitis on my left foot which made it impossible for me to stand. After this, and other complications, it was also confirmed that my first cycle of chemotherapy had failed.

In the following months, further treatment options were discussed, and I was readmitted in December for consolidation chemotherapy. With my blood count literally wiped out again, all hopes for a normal Christmas vanished - it was my first ever Christmas in the ward, but the hospital made it as pleasant as possible with Santa visiting our bed sides with gifts and a special Christmas dinner. By the end of December, my blood counts slowly recovered enabling a discharge on 3rd January 2015.

Unfortunately, following the treatment, it was found that although my molecular level of disease had decreased, my Philadelphia positivity had shot up. It was clear to my consultant that something wasn't

With thanks to Laura Shimili Mears of Laura Shimili Mears Photography for the photography.

Recommended by her post-transplant CNS, Elizabeth found our support groups. We run a variety of local groups and national meetings where you can meet others who share the same experience, as well as learn from professionals from different backgrounds who attend and give talks on a wide range of topics. There is always a place for you at our support groups, so why not find one for you by scanning **here**?

right. In February, the focus became to determine whether I had Philadelphia-positive CML presenting in blast crisis, which would resemble AML, or a rare form of Philadelphia-positive AML. Understanding that would help guide a plan towards having a stem cell transplant, and it wasn't until a year after my initial diagnosis that my diagnosis was changed from AML to CML.

The search for a matching donor then became something to focus on. My family live in Africa so we arranged a test kit to be sent to my sister, who came back as a 50% match which was good enough to give it a go. Unfortunately, luck was not on my side as we were faced with issues getting her Visa application approved for her to come to the UK, but Anthony Nolan found me a 90% match through the stem cell register. I had my stem cell transplant on 17th September 2015 which marked a pivotal moment—a second chance at life.

My transplant recovery has, recurring infections, thyroid disorders, blood transfusion-related accumulation of high levels of Ferritin requiring regular and prolonged period of venesections, and the looming worries that my leukaemia would come back. But, despite my many ordeals, two positive things happened to me post-transplant. First, my Post-transplant Clinical Nurse Specialist (CNS) introduced me to move, dance, feel (MDF) at St Bart's Hospital Maggie's Centre. Second, she also introduced me to Leukaemia Care, whose group meetings, and webinars I enjoy attending and gain useful insights from. These have been eye-opening and great source of information to keep myself updated about new developments and treatments.

The onset of COVID-19 pandemic was a physically and mentally challenging time, especially for people like myself. Yet, amidst the chaos, I found comfort in pursuing the activities that give me the most joy, such as book clubbing; helping out in Cable St Community Garden; participating in MDF sessions; and using Leukaemia Care's services. I also attended counselling sessions, where I have learned the best ways to manage my anxiety and stress from living with uncertainty of cancer.

The dreaded fear of my leukaemia coming back reared its head in June 2022, when my Philadelphia chromosome was detected as positive, triggering a wave of anxiety and apprehension. The subsequent months were fraught with tests and uncertainties, but fortunately repeated blood tests have shown that it has returned to undetectable results.

As I navigate a web of other health challenges, such as high blood pressure, kidney issues, and cervical spine degeneration, I am reminded of the fragility of life. Yet, despite my difficult diagnosis, seemingly poor prognosis, and hard journey with leukaemia, I am grateful to God for still being here for my loved ones and to continue appreciating all the good things in life.

Remembering Phil: Our story

Phil sadly died last year after being diagnosed with acute myeloid leukaemia (AML). Here Joanne recounts her husband's story from the beginning in an attempt to raise awareness of the symptoms.

My beloved Phil was born in 1956; a country boy who grew in to a fit and healthy man. We met, fell in love, and married in 1992 and spent 36 years together.

By late July/early August, Phil had some strange red and purple marks appear on his back. He wondered if he had been bitten whilst we were on our summer holiday, but we figured they would disappear given time.

Then in October, Phil began complaining about toothache and numbness of the bottom lip. He was told he would need four extractions, but hopefully he would be pain-free for Christmas.

A month later, Phil woke with a swollen painful knee - it was so bad he could barely walk let alone drive. I suggested, as we were due to go away for Christmas, he should call the doctors as he still had the marks on his back. The doctor suspected arthritis of his knee, and he was referred to the hospital for a scan as well as a referral to dermatology.

A week later Phil came stumbling down the stairs clutching his chest in agonising pain. I panicked and called 999 thinking it could have been a heart attack. Luckily it wasn't and was related to nodules on the lining of his lungs, they also found signs of an infection, so antibiotics and painkillers got him well enough to return home.

In the run up to Christmas he had biopsies and a blood transfusion. The biopsies showed no sign of skin cancer and Phil was referred to haematology.

In January 2023, Phil had been feeling much better, so we headed to the hospital with hope, but left with more questions than answers.

We were told Phil had acute myeloid leukaemia (AML); he was also one of a small number of patients who deposited rogue cells in other organs in his body; the lumps on his torso were leukaemia cells being deposited in his skin. They couldn't offer him any treatment at the time; it would be a fight that the body couldn't win. We needed to watch and wait as some of his symptoms would return.

We had a routine, I checked his temperature three times a day, asked about any symptoms and reported any concerns to the hospital.

By April 2023, the lumps on his torso had disappeared and he was no longer in pain. However, by May we saw some marks on his head, so I sent photos to the hospital, and they arranged an urgent bone marrow biopsy.

The leukaemia was back, and he needed treatment. We went on a Friday so he could have a PICC line inserted, and we were sent away for the weekend to get our affairs in order; an instruction that made us both catch our breath.

On Tuesday, we got the call to say a bed was available. We remained full of hope; surely a positive attitude would increase his chances of responding to treatment. But the news wasn't good. Phil's kidneys were not strong enough to cope with the suggested chemotherapy, but they could offer an alternative treatment which thankfully had a similar success rate.

Mentally, Phil was ready for treatment, however, I was perhaps more frightened but, there was no way I was voicing my fears and making them real. If he was convinced he was going to win this battle, I would be right there beside him.

By 26th June, Phil's health had deteriorated, he was now struggling to stand, eat and walk. On the morning of his haematology clinic appointment, Phil was admitted and told that the chemotherapy had not been successful. Leaving him alone in hospital that night was one of the hardest things I have ever had to do. We both needed each other; we had always got our strength from one another and now we had a long night apart.

The following morning, we were told no more treatment was available. He could have intensive chemotherapy, but it would probably kill him. We asked how long he had left; a few weeks if the AML killed him, or a week or two if his kidneys continued to fail.

Phil was given the choice of staying in hospital, moving to a hospice, or coming home. The choice was simple. He was coming home. For the past 36 years we had said 'I love you' to each other every day but then we said it every hour, if not more.

We cried together briefly but began to talk. Most importantly, we discussed exactly what he wanted for his funeral. He was so grateful to Leukaemia Care for the cost of living grant we had received - it paid for my fuel for the daily trips to the hospital. So, Phil didn't want flowers at his funeral he wanted donations in the hope he could raise £200 and give someone else the same help we had received.

Within a couple of days, we had completed the important discussions, we needed them out of the way so we could make the most of the time we had left to just be us. Phil made it clear that when the time came it was his wish to die at home with just me at his side.

Over the next two weeks, Phil was visited by friends and family. For the first time in his life, he began to understand how loved he was by so many people. He then started becoming exhausted by the number of visitors so called a halt to visits whilst he regained his strength, which also gave us a few extra hours a day to have quality time together. Over the next two days Phil became a lot weaker and by the Friday we were speaking to hospice staff about what assistance might be available to us.

Sunday 16th July is a day I'll never forget - Phil had another fall, another ambulance call out and at 4pm, Phil lay in his bed, I held his hand and said "I love you". He responded with "love you too" and then took his last breath.

So, that is the end of Phil's story, but it isn't. Our lives were so entwined that 'his story' became 'our story.' Our story didn't end with his death, the days and weeks that followed were the most difficult, but if one person reading this recognises the symptoms, I know Phil's journey will have done some good.

I've recently lost a loved one, who do I turn to?

Finding out your loved one is facing end of life is a big thing to deal with. There is no right or wrong way to feel when receiving this news, and there is no right or wrong way to grieve a loss. But, there are people and places to turn to:

- Our online Bereavement Support Chat allows you to chat directly with an experienced bereavement counsellor between Monday and Friday, 9:00am to 9:00pm. Get in contact **here**.
- Join our Bereavement Support Group, which provides a helpful way to explore feelings and share experiences with the solidarity of others. All the latest details of the next support group can be found **here**. Alternatively, you can join our Bereavement Facebook group **here**.
- Our counselling service offers a grant of up to £420 to access private counselling services for those who are about to or are already experiencing the loss of a loved one. Access the service **here**.

Olga and Anna: Our friendship story

Olga shares her essential thrombocythemia (ET) diagnosis story and how, despite their being nearly a 50 year age gap, has found a friend for life in Anna, thanks to Leukaemia Care's Buddy Scheme.

The Buddy Scheme. Leukaemia Care's Buddy Scheme. A new relationship formed. This is something really important to me, Olga.

In 2021 I was diagnosed with Essential Thrombocythemia (ET) – a rare type of blood cancer. My diagnosis came after I had fallen several times resulting in broken bones and hospital stays. Whilst I was in St George's Hospital, London, abnormalities showed in my bloods leading to my unexpected diagnosis.

It was when in hospital that I was reading a Leukaemia Care booklet and saw that I could speak to someone through the charity. Not necessarily a member of their Patient Services Team but another patient; someone with the same diagnosis as me, being treated like I was, who would have a shared understanding of what this myeloproliferative neoplasm (MPN), ET, diagnosis meant to us both. This is called Leukaemia Care's Buddy Scheme and where I looked for support.

I didn't hear for a while, as with my ET being a rare type of blood cancer there wasn't another patient available to buddy up with at the time I joined. Although it's been a really big part of my life since I was matched with my buddy.

It was after a routine blood test that Anna received her diagnosis of ET. It was suggested to Anna that she join the buddy scheme and pair up with me. There's an age gap of almost 50 years but our relationship still really works for us both. We're also very different people but it works, and I would urge other patients to try it if they haven't yet.

I find with Anna it's like having another granddaughter and I very much enjoy our regular conversations, it's so very nice to have her to talk to - although she does talk like a whirlwind! But I like it! I miss not seeing as many people, and so I like having Anna in my life.

We speak once a fortnight on a Thursday, on FaceTime, sharing family updates, pictures and we understand what it's like to have ET. We approach our leukaemia differently – Anna prefers to know more medically – the blood counts, the levels, but I prefer to not think about mine – if I can't see it I haven't got it, and I can't see my blood! But I'm doing well, and every three months I go for appointments with very nice medical staff, then have my chemotherapy tablets sent to my home.

Anna and I are very fond of each other, I like to hear about Anna's life and I tell her about my children, grandchildren, and great-grandchildren. I lost my beloved husband at the age of 97, in March last year – we were married for 71 years – so I've valued Anna's extra comfort at a difficult time over the past 13 months. We have met up a few times which has been very special too, it's so lovely to be able to meet in person and share a cup of tea and piece of cake that Anna brings to me.

I really hope more people can use Leukaemia Care's Buddy Scheme and experience the sharing of similar experiences - I really enjoy having another family in my life. I always tell people about Anna and the scheme. It's such a wonderful scheme for patients with leukaemia, and a vital service from Leukaemia Care to so many.

Anna says: "I wasn't sure when it was first suggested I buddy up with Olga, I realised she'd be quite a bit older than me, but I wanted to get involved with the scheme as I wanted to give back and speak with people with the same condition as me. I was told Olga was lonely, and her husband had dementia, so I wasn't sure what to expect on first phoning. But she's amazing, such a fun lady and I find it a very positive part of my life. Our calls are full of chit chat and news, and are great for both of us - it's a wonderful scheme. It can be a source of real comfort to people to be able to talk to another person with the same diagnosis who knows exactly what appointments, treatments and experiences they are going through."

With thanks to Laura Shimili Mears of Laura Shimili Mears Photography for the photography.

Would you like to have a buddy, like Olga?

After a blood cancer diagnosis, some people find it particularly helpful to talk to someone who has had a similar experience. They may have been diagnosed with the same condition, faced the same treatment options, and may have shared the same worries, concerns, happy times or sad times.

Our one-to-one buddy support service matches you with one of our trained volunteers for regular or one-off telephone calls or emails.

To find out more about our buddy scheme, email **support@leukaemiacare.org.uk** or call **01905 755977**.

David Lamper: My story

David was 39-years-old when he was first diagnosed with hairy cell leukaemia (HCL) in 2003. Following a relapse in 2010, he was determined to live life more healthily – and now, at the age of 60, he is taking on the London Landmarks Half Marathon.

I first started to become unwell in 2003. I was a 39-year-old headteacher at the time and not one for going to the doctor. I was overweight and my job was stressful, so when I started experiencing what I now know to be leukaemia symptoms, I just put them down to my lifestyle.

I was having night sweats and found myself frequently out of breath. I was bruising easily, was suffering with bleeding gums and nosebleeds, and seemed to be constantly picking up infections. Eventually, after almost passing out while climbing the stairs, I went to see my GP. He suggested I had blood tests. And as soon as he had my test results back, he came round to my house and insisted I get myself straight to hospital.

It was a traumatic time. The weekend of my diagnosis was my youngest son's fifth birthday and not really knowing what was wrong made it a very scary time. My wife, Carolyn, was a GP and clearly had her suspicions. When she trained as a doctor in the 1980s, a diagnosis like mine would have been terminal. Neither of us talked about what was going on - it was all too terrifying. I was afraid that I would not see my sons grow up.

Fortunately, treatments had improved since my wife's medical training. On arrival at the hospital, I was given an immediate transfusion, followed by a heavy dose of chemo through a pump for six days. This was administered as an outpatient. Unfortunately, I suffered an infection caused by the chemo line and ended up spending several weeks in hospital after that.

The chemo hit the cancer hard and I then waited while my body recovered. Six months later, I was in remission and back at work. It had all happened relatively quickly. I got on with leading a normal life, I changed jobs and moved house. After five years, in 2008, I was signed off from my regular medical checks and put the experience behind me.

But two years later, in 2010, I started to notice symptoms again. This time, I acted quickly. I did not allow my symptoms to become as severe as previously and so luckily my relapse was spotted early.

Treatments for HCL had changed since I had last been unwell. I was once again hit with a strong dose of chemo, but this time it was given to me in the form of four injections a day as an outpatient. I was also given another drug alongside it which was a fairly new therapy at the time, targeting the cancer cells specifically. The chemo was grim, but it was effective and because I had not been in such a low place to begin with, I was able to recover quickly. I once again suffered an infection which resulted in me spending a little while in hospital. But overall, I bounced back far quicker than when I had been unwell the first time. A bone marrow aspiration showed no trace of illness and I was in remission within a few months.

I am now in my 14th year of remission and although I insist on regular six-monthly blood tests, I am thankfully doing well.

Over the years, I had put on a lot of weight. But having had my brush with HCL and been given the chance to really live life, I decided that I would be crazy to mess it up myself. So a few years ago, I adopted a healthier lifestyle and with the help of dieting and exercise, I lost 12 stone. I have managed to keep the weight off and decided to take early retirement to really enjoy life to the full.

Having not run regularly since my twenties, I started running with my rescue dog, Hansen, a few years ago. He is a German Shepherd/Rottweiler cross

If you're interested in taking part in a running event, perhaps even a half marathon, we still have plenty of opportunities for you this year! Our Fundraising Team will be on hand to guide and support you through your fundraising journey, whether you're a complete beginner, or a #TeamLC veteran.

Drop the team an email at **fundraising@leukaemiacare.org.uk** and they can help pick the best event for you!

and loves the exercise. I have done a few 5K Park Runs and just before Christmas, I took part in a 10K Christmas Pudding Run.

But the London Landmarks Half Marathon is the first really big challenge I will be taking on. It's very exciting and all my family will be coming along to support me on the day. My aim is to just keep going – I don't want to have to stop and walk along the way. Realistically, I imagine I can hope to finish in around two and a half hours.

I wanted to raise funds for Leukaemia Care because the information they provide to patients is invaluable. The doctors talk to you of course, but as a patient, it is hard to take in all the information, particularly when you are in a state of shock. Following my diagnosis, I read avidly about my condition and wanted to know all about it. The resources provided by Leukaemia Care were key to me understanding my illness. Running the London Landmarks to raise funds for the charity is my way of giving back.

I am proof that an HCL diagnosis is not a death sentence and hopefully, I can give hope to others. Treatments have changed drastically and improved so much over the years. I am certainly proof that you can survive and live life to the full.

Gemma Brown: A mother's unforgettable story

In the summer of 2018, a routine pregnancy check turned into a life-altering moment for mum-to-be Gemma as she faced a diagnosis of myelodysplastic syndromes (MDS). Here she tells her story of strength and love, and takes us through the highs and lows of her remarkable journey.

My story starts on 5th June 2018. I was 27 weeks pregnant and needed to go to hospital for a regular glucose intolerance test as well as my 28-week bloods.

The following day, I received a phone call from the consultant at James Cook University Hospital asking me to come to the hospital straight away. At the time my partner was still at work, so I phoned him and my mum immediately as I didn't want to attend on my own.

Once we got to the hospital, we went to the haematology department where me, my mum, and my partner Craig were taken to a small room. I was saying to them "I must have cancer" but they both said to me there was no way that could be the case.

We sat there and they took my bloods again. A consultant came in with a specialist nurse and it was in that moment that I was told. "You've got blood cancer – MDS". I just couldn't believe it. It was so surreal, such a shock. Looking back, I now know I had many of the symptoms, but at the time I thought these were pregnancy related. My gums had been bleeding, my nose at times, I was very tired, I was bruising, plus there was sickness and weight loss, but surely lots of pregnant women could relate to these.

Navigating pregnancy and treatment

I was told I would need chemotherapy as well as a bone marrow biopsy. The biopsy they could do straight away and it would take 10 days for the results to come back.

The consultant urgently met with the maternity department, as I couldn't start my chemo treatment whilst I was pregnant. They wanted to get me to 32 weeks to help my baby but were worried with my recovery time after the c-section as this would be a further delay to starting my chemotherapy treatment.

I went to the hospital every Monday and Thursday for blood tests and monitoring, and then at 30 weeks it was decided I needed to have a caesarean, and in that moment my baby boy was born, weighing just 3lbs 14oz. We called him Thomas.

On 4th October I started chemotherapy. I was told I'd have to be in isolation for a minimum of three weeks but in the end I was in there for six weeks. Those six weeks were one of the hardest things I have ever had to do in my life, sometimes I felt like giving up, but I knew I couldn't because I needed to get home to my children.

At the time we also had an eight-year-old son Jake – but we hadn't told him I had leukaemia. We said I had an infection and needed to be in hospital or I could get very poorly. Saying goodbye to go into hospital for those six weeks, not knowing if I'd see my sons and family again or come home was the hardest thing ever. My mum stayed in with me the whole time which was amazing, my dad was only allowed to visit for one hour twice a week, whilst my partner stayed at home to look after the children.

During the first 10 days in isolation, everyone had to wear masks and gloves just to be near me. For six weeks straight, I didn't step outside the room unless it was for medical tests like CT scans or X-rays.

On the 13th day, I received my stem cell transplant from a donor as my brother wasn't a match. At the time I was extremely ill, unable to swallow, drink, or eat. I had to rely on a nasal tube, as my Hickman line had become infected. I received blood transfusions

With thanks to Jen Hart of Jen Hart Photography for the photography.

and underwent counselling to cope with being away from my children. In a situation where I craved control, I found myself powerless.

For nearly a year I struggled to do some of the simplest things like walking, eating, and drinking. I had to use a sippy cup as I couldn't drink without one. What hurt me the most was that I couldn't hold my baby for two months after I returned home from hospital. This got me down; I felt like a failure as I couldn't do the things I wanted to do.

Post treatment recovery

Six months after my transplant, we were faced with financial strain, childcare challenges, and health complications, adding just another layer to our uphill climb.

I continued to get infection after infection as well as graft-versus-host disease (GvHD). At the time my muscles were tight, I couldn't straighten or stand up and it impacted my bowels, lungs, and uterus. It sent me into early menopause which was just something else for me to deal with! At 31 years old I was put on HRT, and it took a while to get the levels right for me to feel 'normal'.

Looking to the future

I've been struggling with health anxiety. Thankfully, counselling is helping me cope because I know I can't keep feeling this way forever. It's been a few years, but I'm starting to make progress towards feeling better. Talking about my experiences, even though it's tough, has been surprisingly helpful. I can see some positives now, which gives me hope that I can overcome this. Of course, there are still some tough days where I feel sad, especially when I think about the people I've met since my diagnosis who didn't make it. I feel guilty for surviving, but I'm truly grateful to be alive.

Just before I went for my stem cell transplant, I promised Craig that if I got through it we would get married, and on 6th August 2022, we tied the knot. It was a beautiful and meaningful day to the both of us.

Thomas, now five, brings boundless joy and brightness into my life. Health challenges persist, but with immunosuppressants, regular check-ups, and an unwavering spirit, I continue to embrace life.

My message of hope

In sharing my extraordinary journey, I hope to inspire resilience, highlight the strength found in family bonds, and celebrate the remarkable power of hope. My story is a reminder that even in the darkest moments, there is room for triumph and joy.

Alongside MDS UK, we have refreshed our MDS booklet to keep you up to date with everything you need to know about your diagnosis. Download or order a free copy via our shop, which you can find **here**.

Mark Phillips: Celebrating my 20th anniversary with the London Marathon

Mark was in the military when he started to feel unwell. Putting it down to winter, he couldn't imagine that it would lead to receiving a diagnosis of acute myeloid leukaemia (AML). 20 years later, Mark shares his journey and how this has inspired him to run the London Marathon in aid of Leukaemia Care.

Back in January of 2004, I had begun to feel unwell – nothing terrible but cold and flu like symptoms and I felt chilly much of the time, so I thought it was just that, I had a cold or possibly the flu – it was January after all. I didn't think any more about it, although I was still not feeling any better after four or five days.

I was in the Forces at the time, based in Dorset but originally from Bangor, Northern Ireland, therefore I was admitted to the military hospital to have some checks. It was a further four or five days later when, still no better, I was then sent on to Dorchester Hospital for tests. It was clear by now I was sick, and the tests took a couple of days before the doctor came to see me. It was there and then that they told me I had leukaemia.

It was such a shock! I was only 24 years old! I had acute myeloid leukaemia (AML). This time was just a blur to me. And so I returned home to Belfast.

Within just a few days my treatment began; it comprised of four cycles of chemotherapy. This was a few weeks into January, and all very quick from my diagnosis.

It was only after my diagnosis, and treatment had begun, that it became clear I did have other symptoms but had understandably not made a link to how I was feeling. Also, I had no knowledge of leukaemia or blood cancer so would never have made the connection or gone to a doctor. I had random bruises especially on the upper body and my arms, and these appeared even though there was no contact with anything. I wondered where they had come from but didn't know bruising could be a symptom of leukaemia, I just wasn't aware. All that time, which wasn't even very long in terms of some people experiencing symptoms and looking for an answer, I just thought I had a bad case of 'flu. I was suffering with fatigue, a lack of energy, and headaches – which I'd never previously had a problem with before. It was a very strange experience for me as I had been, and was, very fit, I was in the military after all!

I spent seven months in hospital having my four cycles of chemotherapy. The way it works is to bring your counts down and then build them back up, meaning you start the following cycle two or three weeks after the previous one. In August 2004 I came out of hospital after my chemotherapy.

I feel very lucky. I feel lucky in how quickly I was diagnosed, and how I was able to be treated. I didn't need a transplant, I only had chemotherapy, and if you had met me you would know nothing of that time, not just because it's nearly 20 years on, but not even very long after I left hospital.

Initially check-ups were every three months, then six monthly, then annually up to two years, five years and at 10 years I was moved to self-monitor which is a different checking process.

I now have haemochromatosis – which is too much iron in my blood, but that's it. Again, I feel lucky for that to be it.

I put how I was treated, my journey and the outcomes now, down to the speed of my diagnosis. Perhaps this was down to being in the military, which helped with this. Things moved quickly and I'll always be grateful for that.

I was always quite sporty as a child – playing football, golf and tennis and for a time was in a running club but had actually only run one marathon at 23 years old before my diagnosis. It's been since my return to better health, and now I'm physically fit again, that running has become a much bigger part of my life and keeps me active. I've completed a number of half and full marathons.

I've done the London Marathon twice and have a place to run again this month which I'm really looking forward to. This will be a special marathon run for me as it will mark 20 years since my diagnosis. I'm raising money for Leukaemia Care to help the charity support others of any age who are, and will find themselves, in the position I was in.

I was medically discharged from the Forces two years after my AML diagnosis and now work in Cyber Security. I met my partner in Malaysia in 2017 whilst we were both working in Kuala Lumpur. We spent three years working there and had our daughter. We returned to Madrid where she is from, and it worked for both of us. For me the weather is a bonus as the warmth helps my health – the heat helps me physically and the sunshine helps my mood.

If running isn't for you, replace trainers with pom poms and spur on #TeamLC from the sidelines by becoming a member of our Cheer Squad. There's no preparation required, all we ask is you bring your loudest voice and heaps of enthusiasm on the day.

Want to find out more? Contact our Volunteer Coordinator by emailing them at volunteering@leukaemiacare.org.uk or calling on **01905 755977**.

Rob Colledge: My story

Rob was fit, healthy and active, until he started feeling unwell in the summer of 2023. When an ambulance turned up at his house at 1:30am, he assumed it had got the wrong address, but a diagnosis of acute lymphoblastic leukaemia (ALL) soon followed. 44-year-old Rob shares his story.

I first experienced symptoms in August when I noticed that my right testicle was swollen. I had no pain, but being of a certain age, I was concerned about the possibility of testicular cancer, so I made a GP appointment for the following day. He said it was likely to be an infection and put me on a course of antibiotics.

Two weeks later, I went on holiday to Greece with my girlfriend and two daughters. My testicle was still swollen and, by now, there were a few other symptoms. I was usually a fit and active guy, but I noticed I was feeling out of breath and was using the steps to climb out of the pool. On a night out, I struggled to take deep breaths and my girlfriend became concerned. I was also feeling quite tired and was sweating profusely. I put it all down to holiday overindulgence and did my best to cut down on my intake of alcohol and fizzy drinks.

When we got back home, my girlfriend convinced me to go back to the GP. I told him about all my symptoms and that the antibiotics had failed to clear up my swollen testicle. He sent me for blood tests the following afternoon, and I went to bed that evening without thinking any more about it.

Then in the early hours of the morning, my daughter woke me up to say that there was an ambulance outside the house. I hadn't heard the doorbell ring, nor had I seen the eight missed calls on my phone. I went downstairs, assuming there had been a mistake and the ambulance had inadvertently come to the wrong house. But sure enough, it was there for me.

I was told there was a problem with my white blood cell count and that I needed to come to the hospital. It was a conversation overheard by my two daughters who were at the bottom of the stairs. I called my ex-wife and asked her to come over to look after them and I drove myself to hospital.

I was checked over within an hour and I had my blood taken again and the doctor explained that I might have an infection, but there was the possibility it could be something more sinister. I was admitted to an emergency ward, and by 9:00am the following morning, I was told I had leukaemia.

I knew leukaemia was a type of cancer, but not much more than that. In fact, I had always thought it was something that affected younger people. I wasn't ready for it at all. I made some calls to let my girlfriend, family and ex-wife know what was happening. I was in shock. It was the thought of telling my daughters that upset me the most. It was very difficult for them, especially having seen the ambulance at the house in the middle of the night.

I was discharged and over the next few days, there were various phone calls, until I was called back in and told I had ALL. It was explained that I would need urgent chemotherapy treatment. The aim of the chemo was to get rid of the cancer and I would likely need a bone marrow transplant afterwards to stop it from returning. I am extremely fortunate that both my sisters put themselves forward to be tested as potential donors for me and both are matches.

I have lost weight while on chemo, but I am grateful my side effects have been minimal and apart from a few bad days, I generally feel fine. However, the toughest part has been seeing my children struggle. I reached out for counselling for them and this has been a huge help. Talking to an independent person has helped them to process what is going on.

It is disappointing to know that I face a bone marrow transplant and six weeks in isolation. I struggled when I went through my first round of chemo and that was when visitors were allowed. I went through eight days and I nearly lost my mind, so coping with six weeks of not seeing a soul, especially my kids, definitely fills me with dread. However, I accept that if this is going to give me the best chance of not relapsing, I am all for it. I count myself lucky and remain positive going forward.

Dalata Hotel Group – Our three-year partnership

In 2022 we began a three-year partnership with Dalata Hotel Group and over the course of the three years their fundraising efforts will be helping Leukaemia Care to run a new service – CAR-T Away From Home Service.

2023 saw a wonderful year of fundraising with our corporate partner Dalata Hotel Group. The second year of fundraising did exceptionally well and raised double the amount compared to 2022.

Dalata Hotel Group funds our CAR-T Away From Home service, enabling families to utilise the hotels close to hospitals providing CAR-T treatment, to ensure they can remain together while going through the 30-day long treatment. You can read more about how this service is helping families like Graham and Darcey on page 22.

The Dalata Hotel Group consists of Clayton Hotels and Maldron Hotels. In 2023 teams from both hotels up and down the country took part in everything from the sale of invisible chips, donations for luggage storage and movie nights, right up to taking on the London Marathon and even a skydive.

Some of the best fundraising efforts last year goes to the Clayton and Maldron hotel teams in Glasgow who hosted a range of activities such as 'wear it red' week, Bungee jumping, Christmas jumper day, guess the eggs in the jar and a virtual cycle. Some of their most successful fundraising comes from their regular 12-a-side football matches and between the two hotels they raised over £10,000 for Leukaemia Care.

The fundraising efforts continued with the Cardiff and Bristol hotels also catching the footy bug and hosted their own 5-a-side tournament. Further south the City of London group hosted some brilliant movie nights for families staying at the hotel and the Newcastle group took on the biggest half marathon in the UK - the Great North Run.

Like Blood Cancer Awareness Month, Dalata Digs Deep month is also in September and in 2023 a group of eight volunteers from the Dalata Hotel Group set out on a 1,100-kilometre cycle around Ireland in aid of their three charity partners. They all raised a fantastic amount with the end figure being €38,841!

By the end of 2023 we'd received over £63,000 from the Dalata partnership, which has allowed us to support over 30 families with hotel stays so they could be together while going through treatment.

Looking into this year, the partnership started strong with the inaugural 'Dalata's Got Talent' event which saw heats across Europe, leading up to the final in Dublin in February. The 12 finalists took to the stage and saw the on the night raffle raising over €3,000.

We're grateful for the ongoing support from the Dalata Hotel Group and we can't wait to see all the wonderful things that they do during our third and final year of our partnership, their efforts over the course of the year means so much the families we are supporting.

Do you know a company who might want to support Leukaemia Care though fundraising such as this, or by giving a gift in kind? Please get in touch with the team by emailing **fundraising@leukaemiacare.org.uk** or calling **01905 755977**.

Graham Chandler: Darcey's story

Graham's daughter, Darcey, was four-years-old when she was diagnosed with acute lymphoblastic leukaemia (ALL) in June 2020. When she suffered a relapse in May 2023, her only option was to undergo CAR-T therapy at a hospital many miles from home. Graham explains how support from us helped keep the family together at this very difficult time.

Darcey had never experienced any symptoms in the run up to her leukaemia diagnosis. She was just a normal, active four-year-old.

But in June 2020, she fell off her scooter. It did not seem a serious incident at the time. In fact, my initial response was to simply say to her 'Up you get, you'll be OK'. But by the following day, she was still complaining of pain in her arm.

We took her to a local walk-in centre where something unusual was spotted on her X-ray. Nobody was quite sure exactly what was wrong, so it was decided she would need further scans and at this point, her bloods were taken. The results showed that her blood count wasn't right, so she was moved to our local hospital for further tests. We really had no idea what they were looking for. From our point of view, the worst-case scenario was that she had a broken arm.

My partner, Kelly, stayed with Darcey, and they were moved into a private side room. At this point, we suspected something serious might be wrong. I remember Kelly Googling to see what raised blood levels might mean – and it came up with the possibility of cancer. Darcey's bloods were sent back and forth while the doctors tried to get to the bottom of what was wrong. They were showing as abnormal, but clearly because her ALL was at such an early stage, it was still hard to detect.

The following day, we were told that Darcey had leukaemia – although at this point, it was still unclear what type. It was a total shock. Up until now, we were just a normal family. I had never known anyone who had cancer and I was filled with questions: What does this mean? What are Darcey's chances? What journey will we all have to go on? Everything we were dealing with was new.

At the time, our younger child, Henry, was just a year old, so as a family, we were split up - Kelly stayed at the hospital with Darcey while I remained at home with Henry. It was a very tough time.

Darcey was blue-lighted to London and started chemo immediately. She spent four weeks in

hospital, even ending up in intensive care at one point. There were COVID-19 restrictions in place at the time which meant only Kelly could be with her. The plan was for Darcey to have intensive chemo in hospital followed by two years of treatment as an outpatient.

Despite losing her hair, she handled the chemo reasonably well, but it soon became apparent that it was not working as well as the doctors had hoped, so she was put on a more aggressive treatment. After about 30 weeks, her Minimal Residual Disease levels were still not low enough, so her only option now was a stem cell transplant.

The whole family was tested, but no one was a close enough match for Darcey. Fortunately though, a near perfect match was found for her in a donor from Germany and in February 2021, her transplant took place. Again, she responded very well, with very few side effects. It was deemed a success and she spent the next two years in remission. She went back to school, we went on holidays, life returned to normal.

But in May 2023, she suffered a relapse. It was a shock to everyone, including her consultant who told us it was very rare to relapse this long after a successful transplant.

Darcey had fallen over at school and was complaining about pain in her arm, the same arm that she had originally hurt when she fell from her scooter. We took her to A&E where an X-ray confirmed she had no broken bones. Her blood results were a little strange, but nothing too alarming. We were told she was probably running a slight infection and she was discharged.

Her consultant suggested we do a bone marrow biopsy, just to reassure us there was nothing sinister going on. He was not expecting any cancer to show up, especially with Darcey having been in remission for this long post-transplant. Darcey's arm pain subsided and we got on with life, assuming everything was OK.

But a week later, her biopsy results came back and they revealed that her cancer had indeed returned. It was a horrific shock for all of us and once again we were filled with anxiety over what would happen next and what Darcey's options would be now.

We were told that there was no choice but to put Darcey forward for CAR-T therapy. This would take place at Great Ormond Street Hospital, two and half hours' drive away from our home in Kent. We had no idea how we would manage everything. Henry was now at school and with one of us staying with Darcey in London, the family would once again have to spend weeks apart. In addition, there were the financial worries of the frequent travel costs to and from London, made worse by the fact that Kelly and I were having to take long periods of time off work.

At this point, I was told about Leukaemia Care's CAR-T Away From Home Service which truly provided a lifeline for us at this incredibly difficult time. Leukaemia Care provided us with hotel accommodation close to the hospital so that as a family, we could remain close together, offering emotional support to Darcey and to one another. We were able to visit Darcey during her treatment. Without the grant we received from Leukaemia Care, there is no way we could have afforded to be together and an already difficult situation would have been far more stressful.

Now, nearly eight months on from her treatment, Darcey is doing well. She will remain on maintenance drugs for another two years, but for now, we are hopeful and positive.

Darcey doesn't really understand how seriously ill she has been over the last four years. It is all she has ever known and it's just been a part of her life. As parents, it's hard to look back and remember the times before she became ill, when we were just a normal family without the anxieties we face today. But we are making it a priority to make memories and after so many months of separation, we are enjoying every minute together.

32 patients and their families received a total of 186 nights of accomodation through the CAR-T Away from Home service in 2023.

There are only 17 hospitals that are able to deliver CAR-T therapy. Most applicants travel at least 100 miles to the treatment centre they've been referred to; the additional costs for many families can be a concern.

Our CAR-T Away from Home Service can provide hotel accommodation, with a maximum award of 30 days of hotel accommodation per family.

Get support from Sophie by calling her on **08088 010 444** or messaging her on WhatsApp on **07500068065**, where she can talk you through CAR-T, our service or any other questions you may have.

Nicholas Topley: My story

Nicholas was 49-years-old when he was diagnosed with severe aplastic anaemia (AA). Thirteen years later and currently in remission, he explains how sport and exercise have been key to his recovery, motivation and mental wellbeing. Nicholas shares his story here...

Following a trip to Japan in June 2004, I was diagnosed with autoimmune hepatitis and was treated with high dose steroids. After six months, I was in remission. In 2009, as I was being discharged from the hepatology clinic, I noticed on the blood form that my haemoglobin reading was 11. I was immediately put in the care of the haematology department.

I had had some symptoms of breathlessness when climbing stairs to my car on the sixth floor of the carpark and some tinnitus, but had largely ignored these.

Once I was under the care of the haematologists, despite treatment, immunosuppression and steroids, my condition deteriorated rapidly and I was transfusion-dependent within two months. This allowed me to exist, but by November 2009, I had to stop work. In March 2010, I underwent anti-thymocyte globulin treatment and spent three weeks in hospital. My bone marrow recovered and I was in remission until July 2012 when I started experiencing the same symptoms again. I knew there was a problem, but managed to survive a family holiday in Rhodes before I told my wife that I thought it was the same issue.

By September I was transfusion-dependent and put on the bone marrow transplant list immediately. It was an easy decision to make as treatment was again ineffective.

I received a bone marrow transplant during the Christmas holidays of 2012 from my sister who was able to be my donor. I spent six weeks in isolation in hospital before my marrow started responding and then only very slowly.

The road to recovery was long and rocky (although as the patient you don't really notice it on a day-to-day basis because of everything that is going on). Because I was a mixed chimerism (both donor and my cells in my blood), I was on immunosuppression for almost four years, tapering, increasing, then tapering, before we decided to stop it and monitor it with regular serial bone marrow biopsies; I have had a total of 12.

After six months, I suffered a major setback (thyroiditis) which eventually led to thyroid failure. This necessitated more steroids and I experienced the most unpleasant effects of all the treatment I had ever had. Slowly my condition improved and I went back to work after 12 months, even while still being treated. Once I was free of immunosuppression, my condition improved significantly.

I am currently in remission. My bone marrow function has not changed in seven years.

In 2016, I started cycling. Prior to my illness, I had played sport from the age of eight to a very high standard, everything from football and rugby to cricket, running, golf, tennis and squash. Cycling had me hooked immediately and became an instant obsession. I participated in the Transplant Games in Newport in 2019 and won a Silver medal in my age group. Post pandemic, I won Gold at the Leeds Transplant Games (competing for Team Wales) and qualified to represent Team Great Britain and Northern Ireland in the World Transplant Games in Perth in 2023. There, I won a Gold medal and two Bronze medals, which was a truly incredible experience sitting amongst 2,000 transplant patients.

I have since become a central part of the Transplant Team Wales organisation, with our main aim being to promote exercise in the transplant population as a way of improving wellbeing. This is directed at all levels from beginner to elite transplant athletes.

There is no doubt that sport and exercise have been a massive part of my recovery, motivation and mental wellbeing. I compete regularly in both Transplant Sport and in able-bodied triathlons and sporting events. For my age, I am at an able-bodied level in fitness and performance. To get to this level requires dedication and an elite athlete training regime. Only 1% of Welsh transplantees participate in Transplant Sport, which is far too few. There needs to be a recognition of this and we are working with government agencies and the NHS to promote participation.

Family and friends are critical in your recovery. They do the hard yards that you, as a patient, you do not notice during your brain-fogged ‘me, me, me’ phase. However they see that you are ill every day and without their support, it would have been impossible to recover.

Use your experience to help us to improve the lives of patients and their families.

Nicholas kindly dedicates his time to attend our Patient Advisory Panels twice a year. These meetings are vital for us to be the best advocates and to truly understand the patient experience. If this is something you think you would like to get involved with, we would love to hear from you. Get in touch with our Volunteer Coordinator by emailing them at **volunteering@leukaemiacare.org.uk** or calling **01905 755977**.

Want to find out about our other volunteering opportunities? We have plenty of ways you can get involved and make a difference. Take a look over on our website **here**.

Highlighting our community

All of our fundraisers mean the world to us, and with their help we can continue to support all those affected by leukaemia. However, whilst four days of cycling or running 26.2 miles might not be for everyone, getting out in the local community can be just as impactful. Here are Harry's and Tony's fundraising stories...

Tony's Momentous Miles

On Saturday 3rd February, Tony Pullen and his Dad Christopher, walked 22 miles to raise money for Leukaemia Care.

Tony was diagnosed with hairy cell leukaemia (HCL) in June 2019, and has been living with it even since, having gone into remission in the winter of that same year.

Christopher has had multiple heart surgeries, including heart bypasses, following a heart attack back in 1994, however it was his suggestion to challenge themselves and raise money for the charity dear to them.

It was an early start from Bexleyheath where Christopher lives, navigating London and completing their walk in Charing Cross.

A number of people stopped for a chat about leukaemia, sharing their own stories and personal struggles, whilst congratulating the Pullens for what they were doing with a smile of hope. Tony says this gave them "such an amazing feeling knowing that even if one person is inspired to never give up, it makes it all the more worthwhile".

The Pullen's moto is "stay safe, keep strong and never give up" and this is certainly what they did with their walking – quite a feat for Tony with incurable leukaemia.

Tony said "Leukaemia Care were here for me at diagnosis and still are today; providing the support needed at all stages of our leukaemia and which is so important to patients and their families, so we wanted to raise as much money as we could to help them continue this service. This walk shows that no matter what I'll never give up, I will keep doing what I can to help others and encourage everyone that even when there's no cure, we can never give up on ourselves".

Harry's Heroic Haircut

Four-year-old Harry decided to turn his first proper haircut into a fundraising event. With over 12 inches of hair, Harry's haircut not only marked a significant personal milestone but also became a beacon of hope for children facing hair loss due to cancer treatment.

The decision to support Leukaemia Care was deeply personal for Harry's family. Having lost Harry's Auntie Johanne to acute lymphoblastic leukaemia (ALL) at the age of three, the Botting family understands the profound impact of the disease. The money raised from Harry's haircut is a tribute to Johanne's memory, with every penny contributing to Leukaemia Care's vital work in supporting individuals and families affected by the disease.

Harry's long-awaited haircut took on a special significance as his family also chose to donate his hair to The Little Princess Trust. By sending off Harry's hair, he contributed to the creation of real hair wigs for children and young people who have lost their hair due to cancer treatments or other conditions, providing comfort and confidence to those in need.

The much-anticipated haircut took place on December 29th, adding a sprinkle of excitement to the end of the year. The result? A very different looking but equally happy Harry, who expressed a mix of emotions during the haircut, understanding the greater purpose behind his decision to part with his cherished locks.

In his own words: "It felt funny when they bunched it up and I felt sad when the lady cut it but I know it's going to help poorly children to make them feel good. And I raised lots of money... how much money did I get?"

Harry's Mum Helen said "We chose to raise money for Leukaemia Care because we lost Johanne to the disease when she was just three. For the life she had taken and the child my parents lost, we believe the charity is so important for the support it gives. I once read to lose a child is to lose part of yourself and as a mother anything I, or we as a family, can do to support other people with what we have, we will. This will not be the last fundraiser! Johanne lives on through her nieces and nephews and I hope she's proud of Harry's determination for his hair growth and cut."

Harry's determination and the community's support resulted in a remarkable fundraising success, with over £350 raised. This generous contribution will make a meaningful difference to those affected by a leukaemia, MDS or an MPN.

Want to get involved and start raising vital funds?

People like you, make the essential support that we provide for leukaemia patients possible. Whether you raise a couple of quid or hit the jackpot and raise thousands, the impact of those funds is HUGE.

However, it can sometimes be difficult to know where to start and that's where our Fundraising Team come in. Whether you're running low on inspiration, or not sure how best to organise your event, don't hesitate to contact us.

Our dedicated Fundraising Team are always on hand to give you the advice and support you need to help make your fundraising a success. Give them a call on **01905 755977**, or you can drop them an email at **fundraising@leukaemiacare.org.uk**

Alternatively, you can also find out more on our website **here**.

Hayley Shaw: My story

Just five weeks after being diagnosed with uterine cancer and still recovering from her hysterectomy, 43-year-old Hayley was given the shocking news that she had another form of cancer: hairy cell leukaemia (HCL). As she prepares to start treatment, Hayley shares her story...

It's that moment you think will never happen to you. I vividly recall when I received my uterine cancer diagnosis: Saturday, 17th June 2023. I walked alone into my gynaecologist's room to find him sitting there with a support nurse. It was a gut-wrenching moment that will forever be etched in my memory.

My gynaecologist, who'd been my consultant for over ten years, was usually so happy and upbeat. But on seeing his demeanour, I sensed the news would not be favourable. Then he made the devastating revelation that rocked my world - I had uterine cancer and a full hysterectomy was the only viable cure.

Denial struck me. I was in shock, panic. I was incredulous, unable to fathom the reality of the situation. I told my gynaecologist: "This can't be happening to me. I am a single mother to my ten-year-old son Lorenzo. I have to be OK. I have to be." What we had thought was a harmless polyp removal two weeks prior, was indeed cancer of the uterus. The gravity of the situation hit me like a thunderbolt and I struggled to come to terms with the diagnosis, the prospect of a hysterectomy and the ensuing induced menopause much before my time.

I was scheduled for the hysterectomy two weeks later. I found myself uncharacteristically enraged with the world, resentful that this was happening to me, a single mum with a young child. I tried to hide my distress from my son, often retreating to the bathroom for hours on end to weep in solitude.

As my surgery date grew closer, I became unwell with a bad virus and chest infection. This pushed the surgery back two weeks because the infection wouldn't clear. In the previous two years, I had battled with frequent infections, immense exhaustion, fatigue, bone pain and pneumonia. I always knew in my head something was not right, but doctors could never get to the bottom of what it was.

Surgery day came and after three days in hospital, I was back home alone with my son. This was the hardest point. Not only was I struggling to process the fact that I'd just had major surgery as a result of a cancer diagnosis, but I was pushed into an early, induced menopause with raging hormones. The next weeks were hard, dark and long. But instead of getting stronger, I got weaker and my gynaecologist suggested I see a haematologist for further investigations. Over the next two weeks different blood sampling tests were performed.

Just as I was slowly coming to terms with everything I'd been through in the past four weeks, I was somewhat unprepared for how my world was about to be rocked even more. On the evening of Friday 4th August 2023, I received a devastating phone call that was about to change my life forever... It was from my haematologist who informed me that I had been diagnosed with hairy cell leukaemia (HCL), a very rare and incurable cancer of the blood and bone marrow which only affects around 210 people in the UK each year (Cancer Research UK). Chemotherapy would be needed to put it into remission (which could last for several years), but that each time there is a re-occurrence more chemo would be necessary.

Being diagnosed with HCL is a shock for anyone. Even a lot of doctors have never heard of it because it's so rare. But receiving another cancer diagnosis, alone, via telephone, just five weeks after the first, while still recovering from the hysterectomy, was another devastating experience. It was another kick when I was already at rock bottom. Part of me was relieved they had finally got to the bottom of what was wrong with me over these past few years. But the other part was in utter shock and disbelief. Why, out of all the billions of people in the world, was it me that had to fall into this tiny percentage? Why was this happening to me? That weekend

With thanks to Tracy Main of Tracy Main Photography for the photography.

I cried my entire heart and soul out, unable to process the news.

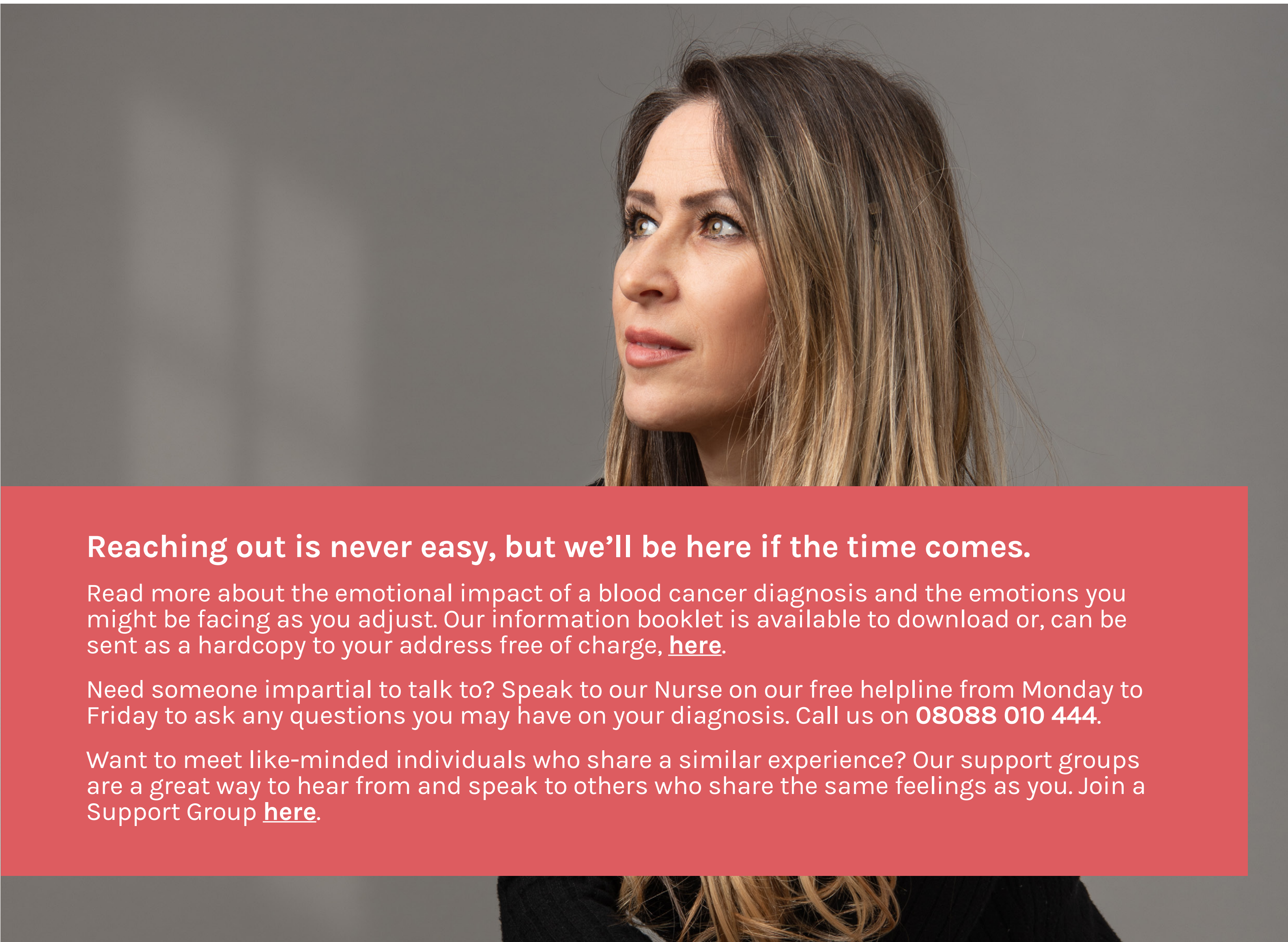
While navigating through Google (which has become my best and worst friend in my weakest moments), trying to learn more about the rare diagnosis I faced, I found a hairy cell leukaemia support Facebook page. This proved to be a source of solace and support throughout that weekend and the subsequent weeks ahead. It is thanks to this invaluable support network that I have been able to get through this challenging period with greater ease, talking to real people with the condition, some that are many months, years and decades ahead of me.

I feel I am not alone and I'm confident that these newfound friendships will endure for a lifetime. In moments of utter weakness, it was these people, who I had never met, who gave me reassurance and from them, I learned how much we rise by lifting others. For every so-called, unneeded friend that left my life, a new meaningful one entered, and what I didn't realise at the time, was that a great filtering was happening. I have spent weeks crying for periods that felt like a lifetime. Every hour felt like a day and every day felt like a week. Some days are a struggle to get through, so I often have to break them down and just work on getting through every hour.

So this is it. I have to look after myself, not just my body, but my mental health too: the way we think can literally change our brains and health. I started doing daily affirmations and expressing gratitude. I also visualise being able to see my boy grow up. I imagine the adventures we still have ahead of us. I made a mood board of places we want to visit, goals I want to achieve. I envisage ticking places off, as well as adding new ones. This keeps me motivated during dark days.

It's not easy being given a cancer diagnosis. It literally tears your heart into a million pieces, and you have to try to pick them up one by one, trying to find a "new normal". I tell my son every day that anything is possible because I've come to realise just how fragile and precious life is.

My journey still continues through this battle. I completed my first round of chemotherapy which was immensely challenging. Chemotherapy certainly takes you to some of the darkest moments that could ever exist and nothing can prepare you for how dark those moments are. Now while living through the aftermath of my first chemotherapy cycle and awaiting my next bone marrow biopsy, I remain hopeful, try to stay strong, and keep trying to make the impossible possible. This is not the ending, this is just one chapter to my story.



Reaching out is never easy, but we'll be here if the time comes.

Read more about the emotional impact of a blood cancer diagnosis and the emotions you might be facing as you adjust. Our information booklet is available to download or, can be sent as a hardcopy to your address free of charge, **here**.

Need someone impartial to talk to? Speak to our Nurse on our free helpline from Monday to Friday to ask any questions you may have on your diagnosis. Call us on **08088 010 444**.

Want to meet like-minded individuals who share a similar experience? Our support groups are a great way to hear from and speak to others who share the same feelings as you. Join a Support Group **here**.

Doreen: My pledge to Leukaemia Care

Doreen was diagnosed with chronic myeloid leukaemia (CML) over 25 years ago, but it wasn't until later in her treatment she discovered Leukaemia Care's Patient Services to support her. Last year Doreen decided she wanted to leave a gift in her Will so others in the future can benefit from the support she received.

In May 1998, as a new chapter began in my professional life, little did I know that my world was about to change in ways I could never have imagined. Around this time, seemingly innocuous headaches and fatigue began to creep into my daily life, prompting a visit to a neurology team. Months followed, and in the end it was a simple blood test which revealed a diagnosis that would reshape my life: chronic myeloid leukaemia (CML).

The journey, from fairly mild symptoms along with my weight plummeting over a stone in just three months, to a concrete diagnosis took eight months. So it was in December 1998, after a routine blood test, that the true nature of my condition became apparent. I received an urgent call from my GP to head to the local hospital – this marked the beginning of a challenging but ultimately triumphant battle against leukaemia.

From January to July 2001, I underwent a rigorous treatment regimen, initially in the form of injections. Subsequently, I joined the tail end of a trial in September 2001, exploring an alternative medication for my leukaemia. The journey was arduous, but today, I am very happy to say that my leukaemia has remained at an undetectable level for the past three years. Remarkably, I even ceased taking medication in January of this year, a testament to the strides in medical advancements.

However, a turning point in my journey occurred in 2020 when, by chance, I discovered a Leukaemia Care noticeboard at my local hospital in Hammersmith. The board showcased the charity's services, support initiatives, events, and fundraising opportunities, opening my eyes to a range of resources available to people like me. Among these services, the charity's helpline became a lifeline for me. The nurse provided invaluable guidance, helping me navigate challenging moments and providing crucial medical advice, preventing a descent into potential depression.

While coping with my own journey I hadn't been aware of the full extent of how Leukaemia Care could help me. The Patient Services team, in particular, became a vital resource for me, offering support and guidance during challenging times. Knowing it's there, ready to lend an understanding ear or provide essential medical advice, has been such an influence in shaping my approach to dealing with leukaemia.

In March of last year, I came across Leukaemia Care's Will service during 'Free Wills Month'. Inspired by my own journey and a desire to give back to a cause close to my heart, I decided to update my Will, adding a pledge to support Leukaemia Care. The process was simple, and I found comfort in knowing that my legacy would contribute to the ongoing support and services provided by this essential charity.

It meant a great deal to me, to support Leukaemia Care, especially considering the staggering number of individuals receiving a leukaemia diagnosis daily. The impact of their services is vast, and I wanted my pledge to play a role in sustaining this vital support for years to come. Having been fortunate in my treatment, I understand the profound impact a gift in my Will could have on another family facing the challenges of leukaemia in the future.

Wills can be a difficult topic to discuss, but it's a necessary step, both for personal peace of mind and the well-being of our loved ones. Through my journey, I've come to realise the importance of being prepared and ensuring that support continues for those facing the formidable challenges of leukaemia.

Over 50% of adults in Britain do not have a Will. Writing a Will allows you to decide how your estate is distributed and gives you the opportunity to give something back to a charity or organisation close to your heart.

We've teamed up with experts to offer a free Will writing service, giving you the chance to draft or update your Will at no cost.

Our partnership provides a convenient and cost-free option for writing or amending your Will. With expert guidance, you can have a well-written Will without any financial burden.

Although there's no obligation to include Leukaemia Care in your Will, we hope you'll consider supporting people living with leukaemia by making a donation.

Choose the option that suits you best:

1. Make a free Will online

We offer two services with Beyond and Octopus Legacy for those who would prefer the use of an online platform to make a simple Will.

A free charity Will written online can take as little as 15 minutes and are checked and verified to ensure they are fit for purpose.

2. Make a free Will at a solicitors office

You can write a Will from scratch or update an existing document at a solicitors office with a local participating solicitor who works in partnership with the National Free Wills network.

The National Free Wills network is currently the only service available for those wishing to make a free Will in Scotland that is provided by Leukaemia Care.

3. Make a free Will via a home visitor or telephone appointment

We've also partnered with the GoodWill Partnership who offer in-home Will writing services as well as telephone appointments.

Once an appointment is completed, you will receive a Will through one of the GoodWill partnerships independent qualified solicitors.

If you have any questions, please do not hesitate to get in touch with us by calling **01905 755 977** or emailing **support@leukaemiacare.org.uk**

To use your free bookmark, cut along the dotted line:

Fact or fiction, we love a good page-turner.

Living with leukaemia, MDS or an MPN and searching for information about your diagnosis can be confusing and unsettling – fact or fiction?

Leukaemia Care
YOUR Blood Cancer Charity

We are here to support you.

Join one of our virtual or in-person **support groups**.

Get one-to-one support from a **buddy**.

Speak to our **advocacy and welfare officers**.

Download or order **information booklets**.

Access our **counselling service**.

Write a **free Will**.

For more information, advice and support:

Go to **www.leukaemiacare.org.uk**

Email **support@leukaemiacare.org.uk**

Call our nurse-led helpline **08088 010 444**

Or message us on WhatsApp **07500 068065**

Keep up to date and follow us on social media:

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Leukaemia Care
YOUR Blood Cancer Charity

To use your free bookmark, cut along the dotted line:

A gift in your Will to Leukaemia Care could help us continue to provide free, clear and accurate information when you need it most.

Our free Will-writing service

Plan for the future by getting your affairs in order.

Find out more:
Go to **bit.ly/HeresHowToWriteYourFreeWill**

Call us on
01905 755977

Leukaemia Care
YOUR Blood Cancer Charity

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