

















Birth of a new life...

For Kate and Lee Hyland, with a transplant AND a new baby on the same day in the same hospital

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> When your brain fog, fatigue, joint paint and insomnia symptoms may not be kidney-related, but could be the menopause

Just YAP-ping

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Meet the amazing volunteer blood runners

Kidney Matters

is the magazine of Kidney Care UK, the UK's leading kidney patient support charity. For 50 years, we have provided practical, financial and emotional help for kidney patients and their families throughout the UK, so that no one faces kidney disease alone.





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...and welcome to our spring issue.

It might be a while yet before summer starts to peek through the clouds, but if you're in need of something to make you all warm inside, look no further than any one of the amazing people we meet in this issue of *Kidney Matters*; each one affected by chronic kidney disease (CKD), but each finding ways to live a good and productive life around it.

People like **Teresa Tandy (page 17** and our front-cover star), a professional dancer with an infectious laugh, who dialyses to treat her kidney disease and receives treatment for breast cancer, but recently completed an arduous 100m trek for charity and, around looking after her two young children, still squeezes so much out of her life.

And we meet **Bharti Brahmbhatt** (**page 34**), who, through determination and the love of her family, turned a childhood experience of bullying by children who did not understand her kidney disease, into a way of helping other people by training to be a peer supporter.

We also look at the treatment and support available if you decide dialysis is not for you. **Consultant Nurse, Karen Jenkins, (page 10)** looks at the option of conservative care, an option offering patients the full support and care of a dedicated team of healthcare professionals, but without dialysis.

Finally, we are very happy to introduce a new regular *Kidney Matters* feature, **YAP**, our chatty perspective on a young life affected by kidney disease, but not defined by it. Our two guest reporters, **Sameer** and **Megan** will take turns to share their take on the highs and lows of being young and really living and enjoying life around kidney disease.

Kidney Matters is your magazine and in whatever way kidney disease touches your life, we'd love to hear from you. This way, we keep each other propped up and ready to face another year! Enjoy the read.

Deborah Duval | Editor

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Front cover photography from Teresa Tandy

Birth of a new life in more ways than one!



Kate and Lee Hyland have a very special relationship – a real labour of love you could say! The couple, who live in Nottinghamshire, met on a blind date more than 20 years ago, bonded over a mutual love of motorbikes, married, and just as Kate gave birth to their first child, kidney patient Lee was also given a new lease of life at exactly the same time...

"I was really unwell with tonsillitis when I was 18," recalls Lee. "When I went to the toilet, I noticed my urine was black. My doctor sent me for tests and results showed I had IgA nephropathy."

Also known as Berger's disease, IgA nephropathy (IgAN) is an autoimmune disease that mainly affects young adults and can go undetected for years before any symptoms start to show.

"In the beginning, I was monitored at six-monthly appointments and because it's a progressive disease, there's no real treatment", adds Lee, who works full time in car sales in Grantham, Lincolnshire.

"Then, when I was 33, my kidney function just dropped quickly. It was all a bit of a whirlwind; I started on dialysis and within 18 months, I had the call for a new kidney."

Baby on the way

During the time Lee was a dialysis patient, wife Kate fell pregnant with their first child. "We chose to have the baby at Nottingham City Hospital because that's where Lee was having dialysis and if he needed dialysis while I was in labour, we'd be near each other," explains Kate.

"The baby's due date came and went, as often happens with a first baby! Then, a few days later, the hospital rang and told Lee: 'We've got a kidney for you; how quickly can you get here?' We put my maternity bag and Lee's hospital bag in the car and drove straight to the hospital.



We were both in the same hospital at the same time, but for very different reasons!

"He had a full day of testing and the hospital confirmed it was going ahead." By this time, it was dark and late, so the hospital let heavily pregnant Kate stay the night in the hospital hotel, usually reserved for people who need to be close by.

Kate said goodbye to Lee, went to the hotel, got into bed...then her waters broke! And everything happened very fast after that.

Family life and a rare diagnosis

"I went into labour and our son Harvey was born the same day Lee had his transplant!" recalls Kate. "We were both in the same hospital at the same time, but for very different reasons!"

The family welcomed baby Amelia a couple of years later, and Lee enjoyed life with his transplanted

kidney for 13 years before it failed. Unfortunately, as an autoimmune condition, IgAN found its way into his new kidney, causing it to decline, and Lee had to go back on dialysis.

But their story doesn't end there. After Lee started dialysis the second time, Kate decided she would begin the process of becoming his living donor and embarked on the raft of tests prospective donors undergo.

However, during the testing process, doctors discovered urine in Kate's blood which led to further investigations. She was diagnosed with a rare, inherited kidney disorder - thin basement membrane disease (TBMD) - which causes blood and protein to leak into the urine. Although most people with TBMD maintain normal kidney function and generally will not need any treatment, it meant Kate





Far left: Kate and Lee at a fundraising cake bake. Above: Lee holding son Harvey for the first time (left) and Kate in training

was unable to continue her living donor journey for the time being. A few days later, Kate, a customer billing advisor at Anglian Water, was talking to her colleague, Stacey Otter, who manages Anglian Water's partnership with Kidney Care UK.

Stacey mentioned the London Marathon in passing and it sparked an idea for Kate. "I'm not the kind of person who likes to sit still, so I wondered how to get healthier for kidney donation," explains Kate.

"I decided to try running and completed the 'couch to 5K', then really got the running bug."

Running towards a target

"When Stacey mentioned running the London Marathon for Kidney Care UK, I decided that's what I wanted to do because I couldn't donate my kidney."

Kate will compete in this April's London Marathon and has been busy fundraising. As well as raising money for Kidney Care UK, running also provides Kate with valuable down time. "It can be quite stressful with Lee's illness, working full time and two dogs and two kids at home.



Kate and Lee's story
is a shining example
of love, hope and
perseverance in the face
of life's challenges



"So, for me, running gives me a release," she adds.

Lee is now awaiting a second transplant and on a mission to keep as fit and healthy as possible. For now, Lee and the children are looking forward to cheering Kate on in London.

"But given our record, I'll be halfway through the marathon while Lee rushes off to have his kidney transplant!" laughs Kate.

Stacey Otter, Anglian Water's Customer Services Partnership Manager and work colleague who inspired Kate's marathon effort, adds: "I have been inspired by Kate's unwavering strength and compassion, since I first met her. Supporting Lee through his CKD journey, raising their family and embracing challenges like the London Marathon showcases resilience and determination. Kate and Lee's story is a shining example of love, hope, and perseverance in the face of life's challenges.

"We were immensely proud to be the first utility company to partner with Kidney Care UK, helping to raise awareness about critical resources like our free Priority Service Register and Extra Care Support."

Further information

- If you would like to sponsor Kate in this year's London Marathon visit: https://2025tcslondonmarathon.enthuse.com/pf/kate-hyland
- To find out more about our corporate partnerships, visit: https://kidneycareuk.org/utilitypartnerships



Brain fog, itchy skin, joint pain, fatigue, erratic periods, poor concentration, hot flushes and insomnia. This sounds like the all-too-familiar list of symptoms associated with having chronic kidney disease (CKD). But for **Queen of Dialysis**, **Maddy Warren**, despite having spent the last 26 years on dialysis, these symptoms were completely alien. Could this, she pondered, be something to do with the menopause?

I have never experienced any of the rubbish symptoms associated with having CKD, because, on nocturnal home haemodialysis (dialysing six-seven hours, five nights a week), I still have blood results equivalent to someone with a functioning transplant, and good health.

This understanding of my normal 'baseline' health was important when this list of irritating symptoms suddenly started during summer 2020. It would have been so easy to dismiss them as just being the unpleasant reality of dialysis, but I knew they weren't, because nothing else had changed. My bloods were good and my dialysis regime and lifestyle remained unchanged.

Insomnia and brain fog

My gut instinct, as a laid-back person who has faced my share of health disasters, was simply to ignore it and get on with life. But the insomnia, brain fog and inability to concentrate affected my thinking – and it really shocked me.

I've always been immensely grateful dialysis has never given me brain fog, since my job is high pressured and busy. I need to handle a lot of information, juggle priorities and make quick decisions across multiple client projects. But the brain fog and lack of quality sleep made my head feel as if it was full of treacle, and my thought processes were frustratingly erratic.

I can't remember...

Post-it notes went from being useful prompts, to irreplaceable saviours containing every professional and personal task I needed to tackle daily. I struggled to find words, remember names or why I had just walked into a room

But it was the onset of very heavy, long-lasting periods, which made my haemoglobin drop, that finally forced me to take the situation seriously. I went to my GP, who thankfully, is an enlightened, proactive doctor and not laser focused on assuming everything must be kidney failure

related, and she immediately recognised my symptoms as being peri-menopausal. As I was only 36 at the time, it came as a bit of a surprise, but also made immediate sense.

The most common menopause symptoms, unfortunately, overlap almost identically with the most common kidney failure symptoms. If you are a woman with kidney disease and you struggle with these symptoms, please consider some of the cause may be hormonal, and if so, treatment is available.

Premature Ovarian Insufficiency

Despite being on dialysis since I was 14 and being extremely well informed in all things kidney failure (certainly my weirdly niche Mastermind specialist subject!), I had never once read about, or been warned of, a possible early menopause. Or Premature Ovarian Insufficiency which is the formal term for menopause before the age of 40.

I was aware of fertility difficulties and that periods may stop, or become erratic when on dialysis, but often stablise with a functioning transplant. Menopause in kidney failure is not well researched, yet we know it is complex and more data is needed.

To cut a very long story short, I fought my way through the system to be referred to a complex menopause clinic which had the confidence







Post-it notes went from being useful prompts, to irreplaceable saviours containing every professional and personal task I needed to tackle every day

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Understand your normal

Maddy's menopause tips!





It's best to understand what is *your normal* on dialysis, and do not assume every new symptom is kidney related. Even if you are too young to expect your hormones to be changing, it's possible they are. There is a lot ation online about being peri-menopausal



of information online about being peri-menopausal and the symptoms are astonishingly wide-ranging.

Start training early for your older lady body. Sadly, menopause causes bone thinning, joint pain, fatigue and increases cardiovascular risk. So does kidney failure. We need to

take that seriously. I have always been obsessed with fitness and have pushed myself hard to find the limits of what I am physically capable of.

I ran the London Marathon in my 20th year on dialysis and am fit enough to climb mountains, hike long distances, do endurance horse-riding and work out regularly. I wish I had started even earlier, but thank my lucky stars I was already fit when menopause reared its head.

I have also learned to be a bit kinder to myself and accept that my body is handling quite a burden now with a heady combination of long-term dialysis and the menopause. I am so used to fighting to stop dialysis affecting my life, and I won't ever stop doing that, or change my optimism and positivity about how lucky I am to still be

change my optimism and positivity about how lucky I am to still be here, thriving. But I am willing to accept that some more sleep from time to time, and a little bit more self-care, won't do any harm!

Further information



For more advice on the menopause and CKD go to: https://kidneycareuk.org/menopause

to treat me. I have been the gobetween, proactively managing my kidney team, GP and menopause specialist to make sure I get the hormone therapy I need, when there is so little reliable data available to these teams on which to base their advice.

The good news is that HRT combined with a tiny amount of testosterone has made a huge difference.

Sadly, it hasn't eradicated my symptoms entirely, as this cocktail of medication is not a magic wand, but they now have much less impact on my quality of life.

This means I can focus on the things that are within my control, as I do with dialysis.

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our new, regular

Young Adult Perspective
column from two
exciting young writers,
Sameer and Megan,
who will take turns to share
insights and glimpses into life
as young adults living with
kidney disease. This issue, we
hear from Sameer...



'You learn to appreciate each day as the gift it truly is'



SAMEER'S MIDNEY STORY

I'm Sameer, a 30-year old CKD patient undergoing haemodialysis. Generally, I'm an extrovert and social person who enjoys seeing friends and family and travelling (health permitting!) I work supporting clients with complex open-source intelligence investigations.

My kidney journey started in April 2020, when my kidneys, unknown to me, started failing.

Navigating those years alone was tough, so I'm just here hoping to make it a little easier for someone else in my shoes.

By Sameer Solomon

Well, here I am, currently sat in a dentist-like chair hoping to get my pearly-whites done. But no, instead I'm at the haemodialysis centre hooked-up for four hours of lifesustaining treatment. That, and the additional waiting time, before and after sessions! Fortunately for me, I have the flexibility of being able to work remotely, so I don't often face the stresses of missing work for treatment or hospital appointments.

It made me think about the adjustments that people with chronic kidney disease (CKD) have to make on a daily basis. From the tiredness and fatigue that kidney failure brings, to the aches and pains doing the smallest of things, to the sleepless nights filled with anxiety and the work-related worries – everything has to be critically considered in our world.

Navigating life is a difficult phenomenon at the best of times, let alone with a chronic illness. My week typically starts off with Monday's madness; thinking about all the work I need to get done, getting to dialysis, dinner plans and, obviously, the upcoming weekend!

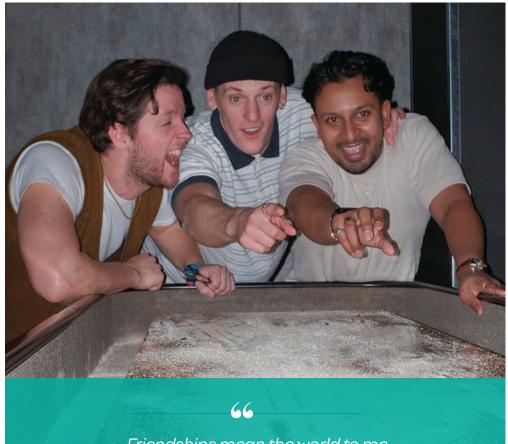
Work life

For many dialysis patients, the ability to work is a real concern. Whether it's working virtually from a laptop or needing to show up somewhere in person, there's always that lingering question: Can I manage it today? I'm fortunate to be able to work from home, but not everyone is so lucky.

Many jobs and industries don't provide such accommodations, leaving patients to grapple with uncertainty. I'm sure many of you reading this can relate to the very real fears of not being able to work, struggling to pay bills or a mortgage, even questioning if you're physically capable of holding down a job. It's a stress that weighs heavily on many of us, adding yet another challenge to an already complex journey.

Home life, food and travel

Feelings of dizziness, delirium and all-round rubbishness are frequent after dialysis sessions, so navigating your way around, whether you drive home from the dialysis centre, or just to do your weekly food shop, dialysis patients can struggle. I tend to drive myself, but sometimes still need a helping hand (my mum) to provide her taxi services.



Friendships mean the world to me.
They offer comfort, support and a sense of normality
in this otherwise abnormal situation

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When you've finally made it back home, you feel ravenous! But instead of eating your favourite foods, or in my case, the unmissable golden arches (McDonald's) which I drive past every session, you need to make sure you're eating the right things. Not too much sodium, not too much potassium – and my arch nemesis – not too many phosphates! There's plenty of foods we shouldn't eat, but you must strike a balance. I find the Kidney Kitchen (www.kidneykitchen. org) is always a good place to look for delicious, healthy recipes!

Once dinner is done, you'll suddenly remember you haven't taken your medication and now need to get them down you – all 12 tablets, in my case! (There's a 'rattle' joke here somewhere...)

More generally, there's other things I worry about; travel, social life and the future. Travelling was a big part of my personal and professional life. I am fortunate enough to have travelled to many places around the world – a luxury I no longer enjoy, but I have dreams to return to this lifestyle.

Those on peritoneal dialysis (PD) can still (hopefully) travel, albeit, lugging a 20kg bag full of dialysis fluid and medical supplies. Naturally, this always raises eyebrows in an airport. Using a disabled lanyard helps to allay these concerns.

Social life

Being a young adult, my social life naturally holds great importance. Friendships mean the world to me. They offer comfort, support, and a sense of normality in this otherwise abnormal situation. Our shared sense of humour, though sometimes sharp, can feel like a shot to the kidneys – pardon the pun.

However, it's not always easy to keep up. The physical differences are undeniable and, at times, hard to accept. Fatigue sets in much quicker, and turning 30 doesn't make it any easier! But despite the challenges, the value of these friendships far outweighs the struggles.

They remind me that laughter, connection and shared experiences are the best medicine of all.

Looking to the future

Who knows what the future holds for any of us? The endless fears we carry on our shoulders every day can feel heavy and are amplified when we think about what lies ahead. For those of us navigating life with kidney disease, the constant dream of a near-normal eGFR (estimated glomerular filtration rate) and the 'normality' that a transplant might bring is a source of hope.

Perhaps, someday soon, things will change. Advances in technology, research and humanity's relentless drive to innovate and improve offer glimpses of a brighter future. Just maybe, these efforts will shrink our fears and turn our hopes into reality.

Life's challenges, particularly those brought on by a chronic illness, have a unique way of shaping and strengthening us. The stresses you face – though often overwhelming – build you into a more resilient version of yourself.

Strength in adversity

When you've had to endure tough times, especially from a young age, you learn to face life with a grit and determination that others may never experience. You find strength in knowing that you've not only faced adversity, but have emerged on the other side of it, stronger, wiser and more empowered.

Living with a chronic condition also changes your perspective. It teaches you to value life in its purest, simplest form. The small things in life; a good day, a cold pint, or even the energy to get through the day, become monumental joys. You learn to appreciate each day as the gift it truly is, celebrating even the 'okay' moments with gratitude. Because when life throws its hardest punches, you come out victorious.

Young
Adult
Kidney
Group

To find out more about our **Young Adult Kidney Group**, go to: https://kidneycareuk.org/yakg

Kidney clinic Conservative care

When dialysis or a transplant may not be the best option

There are many reasons why dialysis, or a kidney transplant, may not offer the best outcome or quality of life to someone with chronic kidney disease (CKD). Karen Jenkins, Consultant Nurse at Kent Kidney Care Unit, explains that selecting conservative care in kidney disease offers patients who have made a shared or individual decision not to have dialysis, or for whom dialysis would not be beneficial, full support and management of their condition in a way that best suits their own

individual circumstances.

We begin to talk about treatment options for stage 5 kidney disease at what we call Advanced Kidney Care (AKC) clinics, supported by a team of specialist multi-professional staff working in kidney care.

Here, at the Kent Kidney Care Unit, we run a nurse-led clinic, referred to as our ASK (Assess and Support in Kidney Care) clinic, where we meet patients who need to be supported through making their treatment choices and discuss all the options. This includes unit-based dialysis, home haemodialysis (HHD), peritoneal dialysis (PD), living donation and conservative kidney care. We recognise each person is unique, with a unique set of circumstances, but conservative kidney care tends to become more of a discussion topic among our older, more frail patients who may also be living with other lifelimiting health conditions.

These clinics are run by an experienced team of AKC nurses and appointments last around 45 minutes, so there is time to talk frankly about each treatment choice's impact. There is no one-size-fits-all in kidney disease. We usually find a

patient will go away to think about their life and whether dialysis is going to benefit them, or disrupt the life they currently enjoy, and then come back with questions. We reassure patients that we are here to answer their questions and support them in whatever treatment choice they



The management of CKD in conservative kidney care is exactly the same as for patients receiving dialysis – bar the dialysis, itself.



make. We take time to explain that, where a transplant is not going to be an option for them, dialysis is not a one-off treatment, but a commitment for life. The reality of that for people with other life-limiting conditions can be what helps them make the decision to be supported through conservative kidney management of

their condition; sometimes referred to as 'palliative or supportive care'.

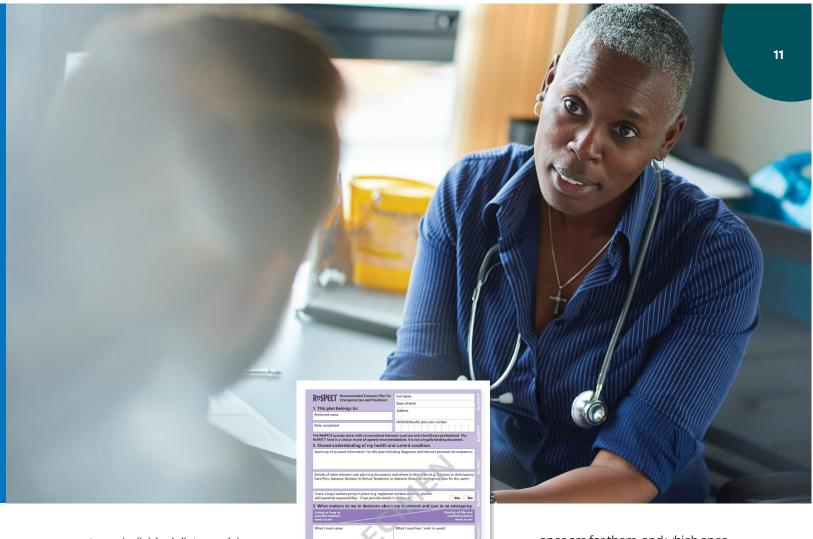
We also take time to understand our patient's wider family and cultural sensitivities. At these times, we emphasise conservative care is not about the end of life, but about keeping our patient as well as possible for as long as possible.

As a Consultant Nurse, I work within our kidney multi-disciplinary team (MDT) and offer patients who've opted for conservative kidney management the opportunity to plan their future care and support, including medical treatment, so everyone is aware of what treatment plan has been agreed. We call this stage 'advance care planning.'

How can you treat kidney disease without dialysis or a transplant?

Our older patients tend to have a sense of their own mortality. Some say: "I'm 85, I've had a good life and just want to spend time with my family. I can still manage a round of golf and walk my dog. That's all I want now." Conservative kidney care offers a whole raft of help and support - including psychosocial support, medication to help manage





symptoms, individual dietary advice and health care planning so a patient's wishes are known when there are hospital admissions. The management of CKD in conservative kidney care is exactly the same for patients receiving dialysis as it is for those electing not to receive dialysis - bar the dialysis itself. Patients receiving conservative kidney care are offered medication to help manage CKD symptoms, such as anaemia or any mineral bone disorder. And if pain relief is required, we support patients with the best treatment for them, irrespective of whether they receive dialysis or not.

People who choose to manage their kidney disease conservatively need to know that we are not planning for them to die – rather, we talk about what they want from life, their goals and what they'd like to achieve. This also includes letting us, and the people close to them, know what treatments or medical interventions they wish to avoid.

The ReSPECT form

To help capture people's wishes we use a valuable electronic form called a 'ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) form, which focuses on the patient's wishes. Along with their medical history and medication, it outlines a patient's life goals, aspirations, any religious beliefs and domestic situation. It also details what they wish to happen if they are admitted into hospital as an emergency and are not conscious, or too unwell, to make their own decisions. It is a formal record, held electronically by their GP and the hospital, and can be shared in an emergency. The patient also has a copy.

Patients can also state on their ReSPECT form what treatments they do not wish to receive – this could be that they don't wish to be treated in an intensive care unit, or do not wish to receive dialysis, or be resuscitated. In reality, a very frail patient may not survive being resuscitated, and while we strive not to frighten people, we do our best to explain the reality of some treatments they may receive in an emergency, so they can decide which

ones are for them, and which ones are not. The ReSPECT form also notes the details of any Health and Welfare Lasting Power of Attorney (or Health and Welfare LPA) that has been put in place so that clinicians know who to contact.

A patient's ReSPECT form may be updated by the patient with their healthcare professional at any time. This is not something you commit to over the course of one day and then forget about it. It is a statement of your wishes and as we know, life circumstances can change, and our wishes do, too.

More information

See our Kidney Care UK patient information leaflet, Choosing not to

have dialysis:

https:// kidneycareuk. org/no-dialysis





'I'd rather have a shorter, happier life'

Conservative care (or conservative management) can be a positive decision for some people with advanced kidney disease who might not benefit from dialysis. They may have other medical issues or feel that dialysis will not help them live longer or offer a better quality of life. **Phil Lockwood**, a retired teacher, explains why he chose conservative care as the best option for himself.

Phil Lockwood's kidney story starts in 2015, when he had a dizzy spell while driving on holiday in Cornwall and his wife, Ruth, had to take over the driving.

"Although the dizziness only lasted for two minutes, it worried me quite a lot. So, when we got home, I went to the doctor to get it checked," explains Phil, who lives in Sheffield.

"She didn't think the dizziness was a problem, but did some blood tests and found I had kidney problems, and I was referred to a specialist.

My kidney function was steadily reducing and I was told that I'd be on dialysis in two to four years.

Quality of life

"But then the rate of decline levelled off and I've got to the stage where it's not worth having dialysis. It's more about the quality of life. So now, the doctors monitor me all the time, just to keep things steady."

Then in 2021, Phil was diagnosed with prostate cancer. This has since spread to his bones, but he still manages to stay positive and is doing well. He credits Ruth, his wife of 54 years, for providing him with a low potassium, kidney-friendly diet. And although unwavering in her support, she admits that it's not all plain sailing. "It does get stressful sometimes," she says. "You never want anybody who's so close to you to be in poor health. And the fact that there is nothing that you can actually do to make it better is hard. But we have a great team at the Northern General Hospital in



It's always on my mind: how long is he going to maintain this level of reasonable health?

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Ruth Lockwood, Phil's wife

Sheffield and we all work together. We go along to an appointment and come out feeling a bit better because they are so supportive. But it's always on my mind: how long is he going to maintain this level of reasonable health?"

Phil decided on conservative care, after initially considering overnight dialysis. "It's so involved," he explains. "You've got to have surgery on your stomach to get the tube in and it just seemed like a lot of hard work to prolong my life. So I'd rather have a shorter, happier life instead."

Phil initially struggled with his decision to opt for conservative care. "I felt isolated," he explains, "I haven't met anyone else undergoing conservative care and I got really depressed because I felt that I was on the scrapheap."

Counselling and a positive attitude

He turned to Kidney Care UK's counselling service for support, which helped enormously. "The counsellor really helped me," he says. "She was great. And I've now got a much more positive attitude. She said to me, 'You've still got things to do. You don't want to go just yet.' And she's right."

Ruth emphasises that conservative care can be a positive option for some. "It's important to say that there is help available with conservative care, including counselling. I also had some counselling with Kidney Care UK and found it very helpful."

Phil, a former secondary school design technology teacher, says: "After I retired 30 years ago, I became





a full-time artist, and as well as painting, I enjoyed making automata (a type of self-operating sculpture/ machine) but these days, fatigue makes it more difficult to work in the workshop, so I tend to concentrate on painting."

Phil used to take art commissions for clients, but this often involved

Retired teacher Phil, painting at home

a deadline, and because fatigue means that he can't work at a consistent pace, he's unable to do this now. If people want a special painting, he tells them: "No problem. I'll do it for you, but can't promise if, or when, it will be delivered."

A little humour goes a long way

Despite his limitations, Phil still manages to get out and about, enjoying walks with Freddie the terrier, pub lunches and attending an art group on Thursdays. Equipped

with a keen sense of humour and a close circle of family and friends, Phil and fellow artist Ruth are determined to make the most of their time together.

Phil chuckles: "Humour goes a long way! We laugh over the silliest things, but you know, it keeps us going."

Further information



To view Phil's artwork, visit: www.phil-lockwood.com

Unsung heroes who are Lifeble d of NHS

Dozens of people are involved in the healthcare of people living with chronic kidney disease (CKD), each one playing a vital part. From doctors, nurses and laboratory staff to friends and loved ones, we couldn't make it without them. But what about those who work tirelessly and voluntarily on our behalf, who rarely make the headlines? Meet the unsung hero 'blood runners' – a dedicated group of men and women transporting blood and other precious items, often under tight time pressures.

The BACKGROUND story

Day and night, rain or shine, all over the UK there are thousands of bikers and drivers delivering vital blood samples, platelets – even human donor milk for premature babies.

Although unfamiliar to most of us, blood bikers and couriers are not a new concept. Yet these unsung heroes and heroines quietly get on with providing life-saving blood and other vital products, often while the rest of us are fast asleep.

Blood biking in the UK spans more than 60 years. Today's blood bikers are part of a network of volunteers, supported by the Nationwide Association of Blood Bikes (NABB) – an umbrella organisation representing individual blood bike charity groups across the UK and Ireland.

Rapid response

All NABB members provide a free, professional rapid response medical transport service to the NHS and most UK Air Ambulance charities.

NABB was established as a charity in 2008, but it can be traced back to the early 1960s. Margaret Ryerson and her husband first devised the concept of a motorbike-based rapid response charity in the UK and formed the Emergency Volunteer Service (EVS) in Surrey in 1962.

These days, there are around 40 active blood bike groups covering both the UK and the Republic of Ireland, each operating separately as



a registered charity. The blood bike and courier industry has become an integral part of NHS front line services, delivering a robust service to professional standards.

In 2021, NABB won the prestigious 'Third Sector Charity Awards' in the 'Small charity, big achiever' category,

and many of NABB's member groups have received the 'Queens Award for Voluntary Service', seen as a type of MBE for charitable organisations.

Front-line service

In 2015, the UK government recognised blood bikes as a front-line service, following years of





BLOOD RUNNER'S story

Mary McMurray | SERV Kent

In Kent, the Service by Emergency **Response (SERV)** team of volunteers provide a courier service, free of charge, to the NHS and Air Ambulance, and are also crucial to kidney patients who dialyse at home and need blood samples transported to hospital within a strict time frame. Operating 24/7, SERV Kent has around 170 volunteers working as bikers or car couriers. All volunteers undergo rigorous training before qualifying as 'blood runners.'

From TV to transporting

For Mary McMurray, her involvement with SERV started around 11 years ago. The former TV producer and director moved to rural Kent after 30 years in London. "I decided to do an advanced driving course, because driving in the country is very different to city driving," Mary explains. "Then I thought, it would be interesting to put it to use



It's a family, a community. I think my friends are intrigued by the fact that you're close to the centre of something that's really quite important

somehow." Mary heard about SERV Kent and volunteered. At that time, the service was mostly about transporting blood between hospitals, but since the pandemic, it has expanded and become a 24-hour service.

Mary became involved with the kidney unit, taking equipment from Kent and Canterbury Hospital out to kidney patients all over the county. She can easily cover 160 miles in a round trip.

And while some volunteers ride bikes, Mary uses a car, which proves useful in many ways.

"You can't transport peritoneal fluid by bike," she explains. "It comes in big, heavy boxes, and if you go over a bump on a bike, you've had it! Temperature is important, too. In winter, car drivers are in demand as the temperature stays constant in a car."

SERV volunteers also face a raft of other challenges to contend with bad weather, dark mornings, traffic accidents, delays, road closures and transporting time-sensitive items, such as blood samples.

But none of these deters Mary, or her fellow volunteers. "It's good fun; it's a family, a community," she adds. "My friends are intrigued by the fact that you're close to something really quite important."

campaigning. The charities can now reclaim VAT and ensure their dedicated fleet vehicles are zerorated for vehicle excise duty (road tax). Today, there are over 4,500 blood runner volunteers delivering an average of 150,000 runs each year, all provided by unpaid volunteers.

John Stepney, voluntary development officer for NABB, and himself a former front-line blood biker with more than 400 'duties' during his time, remembers when he and his colleagues would collect pre-dialysis blood samples from nocturnal dialysis patients.

"We had some patients with a key lock box outside their house," John explains. "They'd put their blood test sample in it, because if they're on the dialysis machine, they can't nip up to the hospital to drop their sample off.

"We'd collect it, which could be any time up until midnight or even beyond in some cases, depending on when the patient was taking their sample." Many things have changed



and all they strive to achieve.

• Continued on page 16

The PATIENT'S story

Martin Eve

English professor Martin Eve knows first-hand how life can suddenly change, but the stress of being a new dialysis patient is lessened, thanks to the SERV Kent team's dedication.

Broadstairs-based Martin, who teaches part-time at Birbeck, University of London, was diagnosed with kidney failure in mid-2022 after a common virus called BK virus (or polyomavirus) attacked his kidneys – most likely due to the high doses of immunosuppressants he has been taking for 20 years to control his rheumatoid arthritis.

Lifelong activity

"By early 2023, I needed dialysis and have been on it ever since," says Martin. "I don't have much chance of a transplant because the virus is still in my system and would just destroy any new kidney. Dialysis looks like a lifelong activity, so I'm trying



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They reinforce my belief that there is good in humankind

99

to get on with it and just make the most of it." Martin recently moved to overnight dialysis, allowing him to have days to himself again. As a home haemodialysis patient, he needs to complete a lot of blood tests from home, but his nearest pathology lab is at Kent and Canterbury Hospital – about 55 minutes' drive away. While transferring to home haemodialysis, he needed to do blood tests every

dialysis session for 10 sessions, with two collections, one before, one after. "Without SERV, it wouldn't have been possible to make the move, and would be a real pain to try and get the time-sensitive samples to the hospital," explains Martin. "It wouldn't be possible for me to work; but instead, there's this fantastic team of people who turn up on my doorstep to take the blood samples back to hospital. My blood collection point is about 11pm and they're always there, rain or shine, smiling. They reinforce my belief that there is good in humankind, these amazing people who volunteer to do this."

An incredible service

As well as collecting Martin's blood samples, the SERV blood runners also take swabs or bring hospital supplies to his door. "It's difficult to imagine how you'd run a home haemodialysis service without them," adds Martin. "I was astonished to find they're all volunteers. It's an incredible service."



HEALTHCARE PROFESSIONAL'S story

Paula Debling, Home Haemodialysis (HHD) Manager, Kent and Canterbury Hospital and Sarah Brock, SERV Kent's voluntary senior controller

Paula (pictured left) and her team's relationship with SERV stretches back to 2011, when they were struggling to obtain a home dialysis

patient's monthly, timespecific blood samples for analysis. She approached the hospital's pathology lab for help, and they recommended SERV.

From night time to 24/7

SERV has expanded its services to provide extra support to the kidney department, including a 24-hour service. SERV riders collect blood samples from all 24 local home dialysis patients, as well as providing urgent deliveries of dialysis supplies

and medications to both peritoneal dialysis and transplant patients.
They also collect prescriptions for home delivery, which has made a big difference to kidney patients, whose reduced immunity puts them at risk of infections and illnesses.

Paula adds: "SERV also provides services to our dialysis satellite units for urgent collections of blood and has become an important part of our work as a HHD unit."

SERV's Sarah Brock adds: "The majority of our daytime runs are now for kidney patients. My granddad died of polycystic kidney disease, so it's a bit of a personal thing for me."

Many of SERV Kent's 170 volunteers also have jobs, so to fit in with their schedules, they are asked to offer a minimum of two shifts a month. Most of them stay with SERV for many years, and they even have a kidney patient who has just started volunteering.

As a volunteer senior controller, Sarah, who joined SERV in 2012, is responsible for managing the volunteer blood runners' rotas and being on-call. "We cover shifts on a rota basis in the same way as riders and the drivers," she explains. "I'll go on a shift with seven other volunteers and we will cover whatever comes in on that shift."

Sarah and her team are also involved in the lives of the patients they serve. "We've had more than one patient ring us to let us know they've had their transplant. It's so nice that they include us, because we're not just a voice at the end of the phone to them."



FEATURE article

Dancing to the

Rhythm of leve

When Richard Tandy walked into his future wife Teresa's studio to hone his dance skills, neither could have imagined that in the next 20 years, they'd become professional dance partners, marry, have children...or that Teresa would be diagnosed with chronic kidney disease (CKD) and stage 4 cancer.

I have always loved to dance and ran a successful dance studio in London, back in the early 2000s. Richard came along to one of my classes wanting to improve his dance technique and before long, we were winning competitions as a professional dance couple.

We were both young, enjoying everything London had to offer and loved to dance. Richard was working as a virologist at King's College Hospital and life was good. Inevitably, our relationship developed into much more than dance partners!

As a child, I had been plagued by recurring urinary tract infections (UTIs), but the cause of these was never investigated, and consequently, never treated. When I was 20, I suffered some extremely painful UTIs and through a Harley Street consultant friend (who offered me 'mate's rates'), I was prescribed rotating courses of antibiotics.

Continued overleaf



• Continued from page 17

It was during these consultations
I first discovered I had reflux
nephropathy – when urine flows
backwards into the kidneys – but as
it had remained undiagnosed for so
long, my kidneys were permanently
damaged.

IVF treatment

Richard and I married in 2008 and both wanted to start a family. We didn't seem to have much luck conceiving 'naturally' so looked to invitro fertilisation (IVF). Our son, Lewis was born through IVF in 2018, closely followed by our daughter, Edith in 2020, also born via IVF.

Both babies were born at King's, where I received amazing care and support from the neonatal team there. The team specialises in caring for women with high blood pressure, and so, were familiar with the additional care my kidney disease required. My kidneys were functioning at around 25% at this stage, but I felt fairly well.



Our son, Lewis was born through IVF in 2018, closely followed by our daughter, Edith, in 2020. Both babies were born at King's where I received amazing care and support from the neonatal team there, who were familiar with the additional care my kidney disease required



Both babies were born prematurely and were delivered by Caesarean section. IVF comes with no guarantees – once again, we were just lucky! Hormones are usually prescribed to stimulate egg production in couples accepted onto the IVF programme.

It makes sense – the more eggs available for fertilisation, the higher the chances of a successful pregnancy. We were no exception, and I was pumped full of hormones in the early stages of each IVF attempt.

A baby during Covid-19

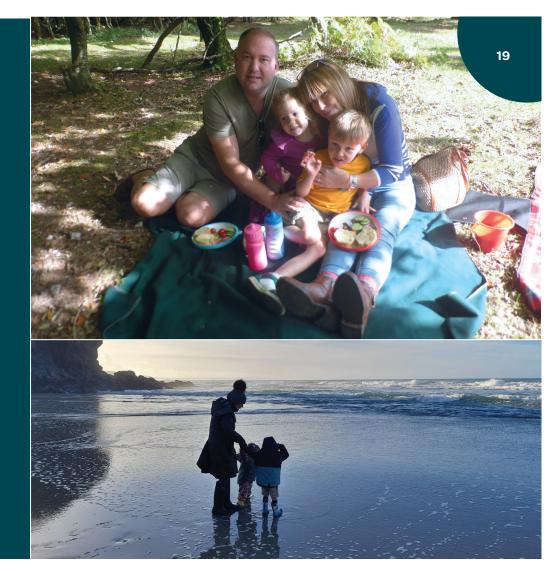
Edith was born during the Covid-19 lockdown, which meant despite the complexities of her birth and my health, we could not be visited at home by a midwife. Edith also has no 'red book' – the Personal Child Health Record (PCHR) – as these were considered an infection risk during lockdown. I had to attend our hospital appointments alone, without Richard – who was a front-line virologist working punishing hours trying to save people struck down by Covid-19.

My dancing also stopped and, as the whole country emerged from Covid-19, we knew we had to change our lives somehow.

Richard researched job opportunities in Cornwall and successfully applied to the Royal



If you ask me what
I want from this life, I'd
have to answer – to see
my children grow into
adulthood, for them to
be happy and have
good lives. That is
what a life well lived
looks like to me.



Far left: Teresa and Richard in their professional dancing days. Left: Teresa during the 100km trek for CoppaFeel .

Above: with Richard and their children

Cornwall Hospital in Treliske, to head up the Clinical Biomedical Sciences department there.

Then, just as we were preparing for the move to Cornwall, I received the devastating news that I had stage 4 breast cancer and secondary bone cancer (bone being the most common site of secondary breast cancer).

Move to Cornwall

The realisation that whatever time I had left with the children and Richard must be the best life possible, also made Cornwall's slower and healthier pace of life even more appealing. So, in 2021, along with my 92-year-old dad, we moved our life, children and all our belongings into a small, rented house in Cornwall.

Six months later, we found a wonderful house to buy - which came with separate accommodation; perfect for my dad, so he could have his own space from time to time. In 2023, I completed a 100km trek for breast cancer charity, CoppaFeel, raising over £3,000 – an amazing experience. Each team of 25 is headed up by a celebrity captain, and our captain was Frankie Bridge (a member of S Club Juniors, The Saturdays and a regular on the *Loose Women* TV show) who also lives with cancer. I applied to take part in 2024, but, by this time, I had started dialysis and had to withdraw my application.

I now dialyse at Treliske, three times a week – while the children are at school and will not miss me. The unit and staff are great, so friendly and welcoming. In terms of treatment for my cancer, I receive a form of directed radiotherapy and remain fairly asymptomatic.

I have a high pain threshold, which I suppose is down to my training as a dancer! I do feel tired, but can't be sure if this is down to my kidney disease, dialysis, cancer or just being a busy mum of two active, funny and boisterous children!

Living with cancer

Lunchboxes still have to be made, uniforms ready and rucksacks packed every morning – even on my dialysis days, when I try to get this done and sneak off to the hospital before they even wake up.

I do ask myself 'why?' Why the kidney disease, why the cancer, why us?

Was it the hormones I had during our IVF treatment that left me predisposed to a cancer diagnosis? I am not sure we will ever know for sure. As for the future, having cancer means I will not be offered a transplant. And whilst my cancer will not be cured, life today is entirely manageable with the help and support of people around me.

If you ask me what I want from this life, I'd have to answer – to see my children grow into adulthood, for them to be happy and have good lives. That is what a life well lived looks like to me.



Per portion cost at January 2025 | Visit www.kidneykitchen.org for more recipes, videos and dietary information

Sausage meatball pasta bake

A quick and simple dish that is sure to be a firm family favourite.

Prep time: 10 minutes | Cook time: 40 minutes | Serves 4



A low-potassium, easy weeknight family-friendly dish, developed by chef Lizzie Morey.



Ingredients

300g pasta shapes of your choice

400g sausages

1 teaspoon olive oil

1 leek, chopped

1 pepper, chopped

1 small courgette, chopped

1 tin (400g) of chopped tomatoes

1 garlic clove, crushed

20g mozzarella, grated

1 teaspoon dried Italian herbs

Method

- Cook your pasta as instructed, drain and set to one side. Take your sausages, remove the skin and discard. Break each sausage into 4 and roll into balls.
- Preheat oven to 180°C / 160°C fan / gas mark 4. Heat the olive oil in a large frying pan and sauté the leeks, pepper and courgette for 2 minutes and then add the sausage balls and cook for 5 more minutes.
- Add the tin of chopped tomatoes to the pan, then fill the empty tomato tin with hot water and add in with the garlic and cook for a further 5 minutes.
- Tip the cooked pasta into the pan with sausage and vegetables, then mix thoroughly.
- Pour the mix into an oven-proof dish. Sprinkle with mozzarella and Italian herbs and cook in the oven for 20 minutes. Remove when bubbling and golden and serve into 4 bowls.

Carbohydrate

Pasta is the main source of carbohydrate in this dish, and the value has been provided for those trained in insulin adjustment.

Phosphate/potassium

Despite the use of some high potassium ingredients, such as tinned tomatoes, this recipe is low in potassium, when following ingredient quantities and serving sizes. It is suitable for those advised to lower potassium in their diet. It is also low in phosphate, but does contain some, mainly provided by the sausages; so if you have been prescribed a phosphate binder, take as directed.

Protein

This dish contains a source of protein and is therefore suitable for those advised to eat more protein.

Nutritional (Perportion) FACTS

Low phosphate ✓

Low potassium **√**

Low salt ✓

Lowin fat X

Source of protein

Carbohydrate 78g

Energy in kcals 639

Taking the lead

By Kidney Matter's roving repawter, Moff



When my hooman, Sharon, announced as the chilly winter approached last year that we would **BOTH** be walking 32.5 miles to raise funds to help Kidney Care UK support even more hoomans affected by kidney disease, I immediately hid! I have very little legs, it was raining outside and I much prefer sleeping and playing with my toys. But from 1 October, we walked and walked and walked around the Hampshire countryside and completed our **32.5 miles representing the 3.25 million people with**later stage kidney disease in the UK. I must say, I'm pooped!



By Pedro
Our Cornish
coastline
correspondent

I took my two hoomans, Amalie (13) and Ivy (13) on several long and short routes around Wadebridge and Padstow. The short walks were completed in the evenings, after school, and the long ones we all did (usually along the Camel Trail between Padstow and Wadebridge) at weekends. My hoomans and I raised a whopping £1,233.16 across our JustGiving page and from money donated by friends.

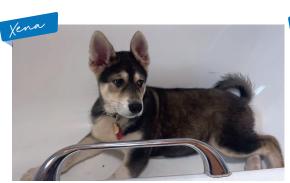
When people saw my lovely Kidney Care UK bandana, I would get lots of attention from people while we were all out walking!

Amalie's mum, Claire, is a kidney patient and dialyses every night and this is why we all wanted to do our bit to raise money to help Kidney Care UK help other people who have kidney disease.





















Main photo: hoomans – Jane, Sheldon and Shelby dogs – Misty, Megan, Bruce, Blue and Rio

> Above left: Young kidney patient James with Paul

Left: Young kidney patient Jason with Stephy

Above right: Oscar and Mabel

By Megan and Misty

Our wagtastic repawters in Preston

Our hooman, Jane Goodeve, who is a Kidney Choice Nurse at Lancashire Teaching Hospitals NHS Trust, loves reading her *Kidney Matters* magazine. When she read about the Dog Walk Challenge in the summer 2024 issue, she asked us if we'd like to do this challenge.

We wagged our tails (which is yes, in dog language) and before we knew it she had roped in colleagues, Carly, Shelby and Laura. We had posters made asking other hoomans and dogfriends to join us at walks planned for all four weekends in October.

Our hoomans asked Kidney Care UK for more bandanas, so that when we were all out walking everyone knew that all of us dogs were walking together for a great cause. Each weekend in October we had about 13 hoomans with their dogs.

Everyone who came along had a special reason for being there; our friend Peggy lost her husband, Roger, to kidney disease and then we had Jason and James who are young adults with kidney disease. Both were lucky enough to be able to attend the Kidney Care UK Young Adults Residential weekend last year.

On our last Sunday Walk, we were joined by Oscar, seven, and five-year-old Mabel, who 'borrowed' a dog for their walk. We were also joined by David, a kidney patient, and his partner Sally, who fundraised for the event amongst her work colleagues and in their village pub. She is a very lovely hooman.

We all raised over £1,200 for Kidney Care UK and at the end of our walks we got loads of delicious treats.

We would like to say a wagtail big thank you to everyone who joined us on our walks and gave us money (and treats).

Dog Walk Challenge 2024







A big thank you from Kidney Care UK to all our furry friends and hoomans who took part!

Writing a new chapter

Kidney patients can spend hour upon hour at long medical appointments, hospital stays or dialysis sessions. For some, nothing beats a good book to pass the time, while for others, an audio book is also a great option, especially if reading becomes difficult due to visual issues or tiredness. Here, we talk to two prolific book-loving authors who are also kidney patients, and discuss audio books with Louise Barling from Listening Books.



You're a hero, Jon B

With over 60 books to his name, including You're A Hero, Daley B, and Little Stupendo (shortlisted for the Red House Children's Book Award) Jon Blake is a prolific children's and young adults' author, as well as an award-winning playwright. He is also an accomplished musician, runs creative writing classes, make documentaries... oh, and he's also a kidney patient on dialysis!



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I started to swell up and couldn't sleep lying down.
I was in a really bad way, but I didn't go to the doctor. Crazily, I was still teaching, playing football and just kept pushing myself

At the age of five, Jon knew he wanted to be a writer after receiving 'The House at Pooh Corner' for Christmas.

"My dad never had a normal schooling, but was self-taught and very cultural," says Jon, who lives in Cardiff with partner, Natalie, and their two teenagers. "I think writing was something he wanted to do, and put it into my mind at a young age that I could do it."

Following a degree at York University, Jon embarked on a teaching career, but still had ambitions to be a writer.

"I studied English and Education, but thought to myself, 'Well, you can't just become a writer, because you have no experience of anything,' so I became a teacher – which I was completely unsuited to – but it provided me with plenty of material! It gave me characters and experience, and I started writing for teenagers," he explains.

His first book was *Yatesy's Rap*, written for young adults and published in 1986, followed by *Showdown*, a book of short stories. His children's book *Thimble Monkey Superstar* was nominated for the 'Lollies' (Laugh Out Loud awards).

Kidney journey

"I first had a kidney problem when I was 41," Jon, now 70, recalls. "I started to swell up and couldn't sleep lying down. I was in a really bad way, but I didn't go to the doctor. Crazily, I was still teaching, playing football and just kept pushing myself. I was getting

palpitations and couldn't eat.
"In the end, I went to the chemist for diuretics. They took one look at me and sent me to the doctor."

Jon had numerous tests at Cardiff Royal Infirmary and discovered his body was full of fluid and his heart twice its normal size. "I think if I hadn't gone to hospital then, I probably would have died," adds Jon.

Not long after, he was also diagnosed with Type 2 diabetes, which went into remission through losing weight and a healthier lifestyle. But more was to come.

The road to dialysis

Before surgery for a hernia, Jon's kidneys were checked and found to be functioning at around 40%. Doctors kept an eye on him, and initially, he had very few issues. However, during the pandemic, Jon became really unwell with a virus (not Covid-19), but because of lockdown, was unable to see his nephrologist and his kidney function dropped significantly. By now, Jon had reached dialysis stage.

"I kept hanging on," he remembers.
"I had a fistula fitted twice, because
the first one didn't work and I didn't
actually start dialysis until October
2023. Nobody told me about the
effect kidney disease has on the heart
and the damage it can cause."

Determined to write

Despite his failing health, Jon continued to write. "I'm so determined and disciplined that







I wrote two novels in the period when I had stage 5 kidney disease!" he explains. "There were only two or three hours in the day where I could actually function at all. I'm happy to be on dialysis because, ultimately, it's a life-saving treatment.

"I was nervous of dialysis at first, but it's a normal part of life now. In fact, I'd probably miss it if I stopped going! It's quite sociable, with a good atmosphere and I get on well with the nurses who are all heroes. Dialysis has given me a new lease of life."

Jon takes his laptop into the dialysis unit and is usually working while other patients sleep or watch TV.

Jon states: "I'm always prepared and have a timetable for the four hours I'm dialysing. Sometimes I'll edit a music video, or research a book."

Plenty more to do

Jon wrote his latest book, Second Quality Dragon, as a kidney patient and revised it while on dialysis.

According to Jon, being on dialysis has brought a different way of writing.

"It's made me more clear-thinking and succinct," he says. "However, to be creative you've got to feel on top of things. So, something that used to take me a month to complete, might take me three months now, because

Author Jon Blake at his Cardiff home

of my lower energy levels." After 40 years, Jon's passion for writing hasn't waned and he still has plenty of projects on the go.

"My motivation has always been to get more children and young people to read. I've still got a few books I've written that I want to get published. I made a documentary, Roald Dahl and the real Mrs Pratchett, and may do another one."

• Jon's latest book, Second Quality Dragon, is due for release end of February 2025. Available from jonblake.co.uk or Amazon.

How the grandchildren I never thought I'd meet inspired me to write



From army gunner operator and champion angler, to drag artist and author of 19 self-published books, **Brian Bennett** lives a full and very colourful life, all while managing the kidney disease he developed 60 years ago.



Brian at home in Evesham

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My daughter said, 'I'm pregnant, dad.' Those words saved my life.

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Lively 71-year-old Brian is the versatile author of children's and young adult books, as well as adult thrillers, erotica and ghost stories.

One of his stand-out publications is A Walk With Grandad, the book that kick started his writing career and one he wrote for his future grandchildren whom he feared he would never meet. He even credits his eldest granddaughter for saving his life.

From despair to delight

"I decided to write a book to leave to my future grandkids and for the ones I'd never see. At the time, my second transplant had failed and I'd been in intensive care for a while," explains Brian, who lives in Evesham.

"When I came out of hospital, I said to my wife, 'I can't do this anymore. I've had enough'. We discussed it and we talked to our kids about it, and we were all in agreement that I was going to come home from dialysis one day and that would be it. I wasn't going back. I was just going to pass away quietly at home.

"My wife and daughter came to pick me up from hospital to take me home. I said goodbye to all the nurses and doctors, but when I got to the car, my daughter said, 'I'm pregnant, dad.' Those words saved my life."

Now 12 years old, he describes his granddaughter as 'my world'.

"Every time I see her, she gives me a hug and a kiss and says, 'love you, Granddad'." Now with two granddaughters to keep him on his toes, Brian's zest for life is what keeps him pushing through. But about four years ago, he hit another low point.

"I felt like I had had enough," explains Brian. "I drove to the South Coast, ate breakfast every morning, went out for meals and drank cider. The police caught me as I was driving through Weston-Super-Mare.

"I'd been gone for four days and people were looking for me. That feeling of wanting to end it all has never left me. It's always in the back of my head. But the thing that keeps me going is my grandkids."

Brian is the ultimate survivor. He's already confounded doctors' predictions that he'd be lucky to live to 60. He's been on dialysis for 32 years, survived sepsis twice, has had six mini strokes, two failed transplants and numerous operations.

Comedy drag act

He's also raised thousands of pounds for different charities over the years, mainly by doing a comedy drag act as 'Tina Burner', 'Shirley Trashy' or 'Marilyn Moanrow'. He was even *Kidney Matters*' wonderful 'cover girl' for our summer 2020 issue!

But nothing stops Brian's creativity.

"At school, I decided it wasn't for me," recalls Brian. "My education was very poor, and I wonder now if I was on the autism spectrum, but then I have written all these books and am still going strong with another novel about to be published, so I must have learned something along the way!





Brian as 'Marilyn Moanrow'

"I write whatever comes into my head and I've never got the middle or an end of a book, I've only ever got the beginning. Sometimes, if I have a problem with a certain part of the book, I go to sleep thinking about it, and when I wake up in the morning, somehow I've answered it.

"How does that work? I have no idea!"

Brian uses his time on dialysis to write, and his new novel, *The Bosses Shadow*, will be published this year and is available from brianbennettbooks.com

"I write books because I enjoy the whole process," says Brian. "And I have one remaining ambition – to take my grandchildren into a bookshop and show them my books on the shelves."



Read more on Brian's incredible journey through life and kidney disease in our summer 2020 issue at: https://kidneycareuk.org/kidney-matters-issue-9



These books are made for talking...

For those with visual or physical issues, or people who find kidney disease exhausting, reading can take up a lot of precious energy and some may feel they're missing out on a once favourite activity. But help is at hand with Listening Books...

Listening Books is a non-profit organisation committed to providing audiobooks to people from all walks of life. From busy mums on the go, to commuters and those living with illnesses such as chronic kidney disease (CKD), they offer a huge variety of audiobooks for every taste.

Louise Barling (*pictured right*), Membership and PR manager at Listening Books, explains: "We're a charity for anyone in the UK who has an illness, disability, learning difficulty or mental health condition and cater for both children and adults."



The charity is also involved in many community projects. It gives tablets to children's hospitals and to hospices, setting them up with wireless headphones so patients have access to books while in hospital or the hospice.

Audio books also provide a welcome distraction while dialysing. "A lady contacted us to say both her children have kidney disease and need dialysis," Louise recalls. "Listening to audio books helps pass the time, but they also soothe the children by lessening the noise caused by their dialysis machines."

No barriers to membership

Membership costs £20 a year, but Louise believes there should be no barriers to joining, especially a financial one. "It's important that everyone has access to audiobooks. If someone is struggling to pay, they can let us know when signing up by ticking a box. This allows us to offer free membership, and we take this completely on trust."

In the past, there was a delay of sometimes up to a year between a book being released and its audiobook counterpart coming out, but now, audiobooks are available alongside hard copies and seen as a genuine option for many people.

Louise firmly believes that, even in this digital age, books still have an important role to play. She concludes: "Members get in touch, sharing that Listening Books has been a lifeline for them, and helped relieve feelings of pain and loneliness. For some, Listening Books has provided them with a story to escape into, and for others a sense of connection with the world when maybe their world has got a little bit smaller through illness or disability."



For further information visit: www.listening-books.org.uk

Jour #BloodyAmazingKidney stories

In our last issue, we told you about our **#BloodyAmazingKidneys** awareness campaign – and thank you so much if you shared the poster we featured, or if you supported us by emailing your MP, sharing it on social media or by sharing your experiences with us, and the media.

In the first month alone, over 110,000 people completed our online Health Checker, with around 50% of those identified as being at increased risk of chronic kidney disease (CKD).

We gained support from MPs and MSPs, as well as many medical practices, who shared the campaign on social media and with their patients.

Our campaign was featured in more than 300 pieces of media coverage, and over 1,500 people scanned our posters displayed in washrooms at locations across the UK.

But, we're not resting on our laurels, and you'll see more of our #BloodyAmazingKidneys work in 2025 and beyond.

We're speaking to the NHS to see how we can get the message out to GP surgeries and clinics. With the new NHS 10-year plan focusing on prevention, we have a real opportunity to show policy and decision makers just why our kidneys are so incredible.

But what really resonated with us, as a charity, was the number of stories shared by people across social media and on our website.

We wanted to share some of these with you in case any of their experiences help you to know you are not alone. We don't think awareness of kidney disease is anywhere near where it should be.

And we want to change this, as well as provide support to all of those who need it – you do not have to face kidney disease alone.

110,000

people completed our online Health Checker in the first month alone! 50%

of those identified as being at increased risk of CKD



Dee's story

Kidney Care uk



"I developed an infection in 2018, which damaged my kidneys and resulted in a stay of almost nine weeks in hospital. When I was discharged, I left with a diagnosis of stage 4 $\,$

CKD, but have since discovered there were six blood tests between 2016 and 2018 that showed my kidney function was declining, but no one picked up on it, and no one told me. I feel passionately that we all need to talk more about our kidneys and kidney health, which is why I support the #BloodyAmazingKidneys campaign."

Dee, Diary of a Kidney Warrior Podcast







"I was diagnosed at university, after seeing various GPs, who at first provided no real answers. A simple urine dipstick test prompted further hospital investigations, including a biopsy and I received a diagnosis. My confidence plummeted; none of my peers had anything like this and I went from being fit, active and healthy to someone who often had low mood and poor mental health. I often wonder if my life would have been different if I had been diagnosed earlier, or given more mental health support when first diagnosed. That's why the #BloodyAmazingKidneys campaign is so important – the earlier you are diagnosed, the more there is you can do."

Nick, Patient Ambassador and Involvement Lead at Kidney Care UK

Becky's story



"Looking back, there were so many signs that something was wrong with my kidneys. I had various indicators at different points in my life – itchy skin, swollen hands. I either put it down to exhaustion, or just shrugged it off and carried on. But, like many people with CKD, if I'd known more about the symptoms, I might have realised what was happening sooner. I've always been fit and healthy – I train, swim, lift and run marathons and generally follow a clean lifestyle. Then, I just collapsed, and everything changed overnight. More needs to be done so people are aware and recognise the symptoms of CKD, which is why I think the **#BloodyAmazingKidneys** campaign is great."

Becky, former body builder, only recently diagnosed with kidney failure caused by Minimal Change Disease, at the end of 2024



| Izzy's story



"There was an opportunity to spot my kidney disease at least 15 years before I was told I had it. I think the **#BloodyAmazingKidneys** campaign is fantastic; something bold that will make people pay attention, because not enough people are aware of the signs that their kidneys might not be working as they should. I've found this is especially true within the Asian community, so I would urge everyone, especially people who are more at risk because of high blood pressure or diabetes, to get themselves checked out, just so they can be aware of what they should, and shouldn't, be doing to protect their kidneys."

Mohammed 'Izzy' Islam, Kidney Patient Involvement Network facilitator and dialysis patient

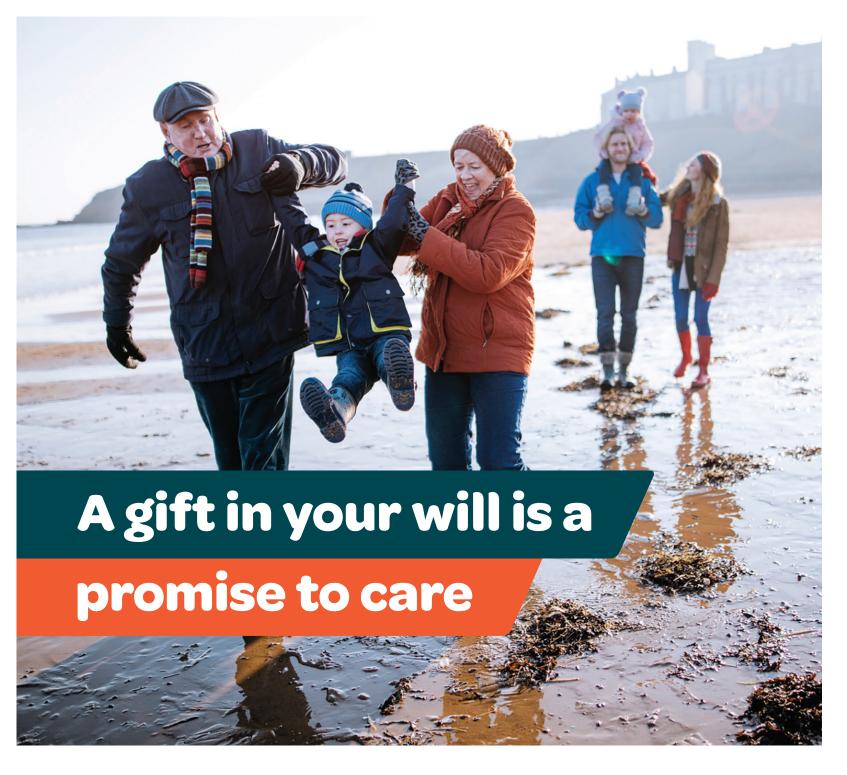


You do not have to face kidney disease alone. If you need support, we are here.

Call us free on

0808 801 00 00 (Monday to Friday, 9am-5pm)

support@kidneycareuk.org | www.kidneycareuk.org



Your promise will ensure no one faces kidney disease alone.

We promise to provide the very best practical, financial, and emotional support to kidney patients and their families, whilst also campaigning to improve care services for everyone affected by kidney disease. With your help, we can make sure that these vital support services are available for years to come.

Get in touch to find out more

www.kidneycareuk.org/promise | 01420 541 424 giftsinwills@kidneycareuk.org











Lobbying parliament for transplant improvements

With the transplant waiting list at a 10-year high, Kidney Care UK hosted more than 60 MPs and peers at an organ donation parliamentary reception, held jointly with NHS Blood and Transplant.

Everyone attending last December's event, hosted by Florence Eshalomi MP, heard first-hand from people affected by kidney disease how the condition impacts their lives, the difference a kidney transplant can make and how challenging the wait for a suitable organ can be.

Ms Eshalomi, whose mother had been on dialysis for 11 years, was joined by Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health. The Baroness encouraged people to make their organ donation wishes known, add their name to the organ donation register and talk to family about their decision.

Early intervention needed

Fiona Loud, Policy Director at Kidney Care UK, spoke about the need for earlier identification of kidney disease so that fewer people would face kidney failure in the future.

"With the transplant waiting list so high, it is vital that increasing demand for transplants is carefully considered by the government and NHS," says Fiona. "Early intervention and prevention of chronic kidney disease (CKD) must be a key part of this, given that the opportunities and new treatments which do exist are not being used to their full potential."

Jess Harris, from London, told the audience about having diabetes aged 11 and how her subsequent kidney failure had been difficult. She explained the life-changing difference receiving 'Kev the kidney' and 'Pat the pancreas' had made, enabling her to have a baby with her partner.



Lesley Coles (left) with Fiona Loud, Kidney Care UK's Policy Director, at the reception

"I went to Parliament as this is a cause vitally important to me and my family, explains attendee Lesley Coles, from South Wales.

Stressful time

"The subject must be raised as CKD seems to be the 'forgotten' disease and hopefully, by us engaging with the MPs, we gave the importance of organ donation a lot of publicity. Being on the transplant waiting list is a very stressful time – this awful disease and the consequences of being on the waiting list needed to be brought to the attention of as many people as possible," adds Lesley.

"I discussed with MPs the lifechanging impact my kidney transplant had on me. My transplant enabled me to have a life and see my children, and amazing grandchildren, growing up, plus be able to work and do normal everyday things people without CKD take for granted." Fiona concludes: "We would like to thank you if you supported the event, either by writing to your MP to urge them to attend, or making the trip to Parliament. Kidney Care UK has contacted each of the parliamentarians who attended to thank them and ask for their ongoing support in working for better care and support for everyone with kidney disease."

Further information

To join our campaigners' network visit:

https://kidneycareuk.org/kidney-care-campaigners



AN AMAZING

£2.3m

raised by our incredible fundraisers and supporters



OVER

500

kidney patients and their families helped every month



AROUND

£1.5m

in benefits income secured for families facing hardship



MORE THAN

supported with

counselling, advocacy
and debt advice



Making an impact

Our *Impact Report*, summarising our achievements in 2023, reminds us how many people with chronic kidney disease (CKD) we've reached – as well as how many we still need to reach to continue our mission 'to improve the quality of life of everyone affected by kidney disease.' Here's a snapshot of the report's highlights...

Welfare and grants

One of our biggest achievements is the one-to-one support our team of Patient Support & Advocacy Officers (PSAOs) has given to almost 3,000 new patients across the UK, providing personal and confidential support to them. Around half of those we support experience financial hardship, exacerbated by their treatment's impact, which makes navigating the welfare system difficult. This means many do not receive the financial support they are entitled to. In 2023, we secured over £1.5 million in unclaimed welfare benefits for people with CKD.

We also awarded 1,593 grants in 2023, providing £806,165 in financial support to patients and families.

Mental health

People with long-term health conditions are twice as likely to

develop mental health problems and struggle with their emotional wellbeing. Kidney Care UK offers free specialist counselling, providing emotional support to people affected by CKD. Our British Association for Counselling and Psychotherapy (BACP) accredited counsellors are qualified in counselling therapies, but also understand kidney disease, its impact and treatment.

In 2023, we introduced two additional counsellors to help meet demand, supporting 324 patients and delivering over 1,800 counselling sessions. We were able to maintain a waiting list of just four to six weeks for much of the year, compared to much longer waits for NHS services.

Money and energy advice

Thanks to British Gas Energy Trust, we were able to create a specialist,

in-house Money & Energy Advice Service (MEAS) in June 2023, to help patients access to welfare support and to manage soaring utility costs.

Our three new Money & Energy Advisers understand welfare benefits and financial support available for individuals affected by CKD, but also understand what it's like to live with kidney disease.

Working closely with our PSAOs, they provide a valuable resource that enables us to achieve better outcomes for individuals. We received 156 referrals to our Money & Energy Advice Service in the first six months of the service launching.

Young adults

We've also enjoyed seeing our online Young Adult Kidney Group community (YAKG) go from strength to strength, with around 1,000 members regularly engaging. This



100th





web sessions for **Kidney Kitchen** where you'll find

200+ kidney-friendly recipes





• For our Impact Report: https://kidneycareuk.org/our-impact

- Visit our Kidney Kitchen: https://kidneykitchen.org/
- For benefits and money advice: https://kidneycareuk.org/getsupport/ or call **0800 801 00 00**
- New episodes of *Diary of Kidney* Warrior Podcast are available to
 download every other Monday from
 Podbean, Apple Podcast and Spotify.
 Episodes also available on YouTube
 or via https://kidneycareuk.org/get support/podcast/

private, moderated Facebook group is an exclusive space for people aged 16 to 30 to share their experiences in a supportive way, reducing feelings of isolation and loneliness.

Our annual Young Adults Weekend at Mount Cook in Derbyshire is becoming increasingly popular, with an average of 50 attending the weekend of fun, activities and friendship. We also provide a national peer support service, run by young adults for young adults, and our nine trained peer supporters provided personal one-to-one support to over 100 young adults in 2023. (see our brilliant new Young Adult's YAP column on page 8, too!)

Website, podcast and digital tools

Our website was also a big hit, and, for the first time ever, we had more than 1 million users visit our website and over 2 million page views across the year. Our popular Diary of a Kidney Warrior podcast, run in collaboration with podcaster and patient Dee Moore, reached a milestone 100th episode in December, and was downloaded 13,934 times across the year.

Our Benefits Calculator – a free, online digital tool to help people

identify any benefits they may be entitled to, but are not currently claiming – has been popular, too, with 1,833 using the tool during the year. This laid the groundwork for our PIP Helper, a complementary digital tool, launched last year.

Kidney Kitchen

Our ever-popular Kidney Kitchen continues to thrive and expand, with the Kidney Kitchen website reaching an incredible 270,000 web sessions in 2023. The site offers 200+ kidney-friendly and delicious recipes, created by talented chefs and kidney dietitians and includes food facts, dietary information and videos.

In the media

Our marketing and communications team works hard to increase awareness of the charity and the support services we offer. We achieved 962 pieces of media coverage, in 2023 reaching a combined audience of 44.8 million people, the majority of these (85%) were broadcast media (TV, radio or online).

Policy team

Our policy team strives to champion the issues that matter most to the kidney patient community. One highlight was seeing Northern Ireland become the final four-nation country to introduce an opt-out system for organ donation, after many years of campaigning and lobbying by Kidney Care UK.

Fundraising

Despite the continuing cost of living crisis, in 2023 our wonderful supporters and funders excelled themselves, generating an amazing £2,340,889, an increase on the previous year. As we receive no funding from the government, our vital services would not be possible without the generosity of our incredible supporters.

Kidney Matters

And last, but not least, we're delighted that *Kidney Matters* continues to reach out to the kidney community. More than 20,000 copies per edition went out to patients and health care professionals in 2023, and we'll continue to share your amazing stories and be the voice of our kidney community.

So, a huge thank you for your ongoing support.
We really can't do it without you!

By Bharti Brahmbhatt

A lifetime of illness and bullying spurred me on to help people

When vesicoureteral reflux (VUR) was confirmed in their little daughter, Bharti Brahmbhatt's exhausted parents were not to know the diagnosis would lead to bullying and a life plagued by poor kidney function. Now a mother of two sons herself and training to become a peer supporter, Bharti draws on her own life experiences to reassure other patients that a life with kidney disease is one very much worth living.

Early years

I can't remember much about my very early years after we had moved to live in the UK from Surat Gujarat in India. I was about four years old and still wetting the bed. Changing my bed every morning exhausted my mother and at that time, our local GP could not throw any light on what was causing the problem.

My mother tried everything, from awarding me a gold sticker if I made it through the night with a dry bed, to withholding all drinks from me after 6pm. Nothing worked and the knowledge that I would soon have to start school added to their concerns.

My parents, Narsihbhai and Shardaben, worked hard in Bradford factories at that time and we did not own a car. But my father found a specialist in Leeds who might be able to help us with a diagnosis and treatment. It would be a private appointment, but somehow, they found the money and we all travelled to Leeds on the bus

Paying privately for a diagnosis

I was diagnosed with vesicoureteral reflux (VUR) – where urine flows backward from the bladder to one or both ureters, sometimes to the kidneys – and admitted to hospital, where I stayed for two weeks. I was



I started school where the bullying was relentless – children can be cruel sometimes

-90

five years old, very small for my age and had to be left there alone as my parents could only visit once a week by bus. They must have been so worried, and it was a terrifying time for me, too. It was the 1970s and the medical investigations cost my father £200, which was a lot of money for them. The medical team confirmed I had kidney disease, which was causing my constant bed wetting and recurring urinary tract infections (UTIs). The consultant also confirmed it was likely I had been born with reflux, but this was the first my parents knew about it.

Ureteral reimplantation

Soon after this, I started school, where the bullying was relentless. Children can be cruel sometimes. They teased me and called me 'wee-wee girl'. I was so unhappy and so afraid all the time. I tried to explain what was happening to my teacher, but she told me to stop telling tales.

My medication tasted awful and made me sick. But when I was seven years old, we discovered I needed an operation called a ureteral reimplantation, where a faulty valve between the bladder and the ureter is repaired. We all thought this would fix the problem, but it did not and soon I was back in hospital having more surgery to repair the other ureter. I missed a lot of school because I was always at hospital appointments, or in hospital having surgery. This affected my self-confidence and mental health.

I carried on, tolerating the bullies at school, but by the age of 11, I was



I have always wanted to use my experience and my love of chatting to people (I speak four languages) to help others facing kidney disease. I do really believe it helps to talk to someone who has been through it

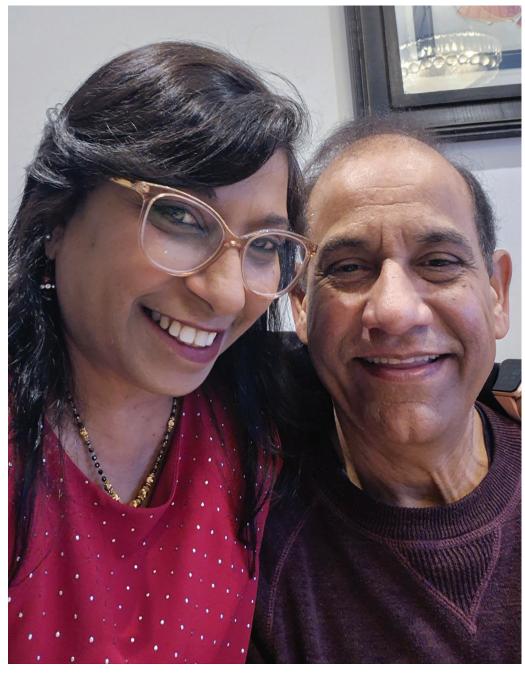


poorly again. This time, I needed my right kidney removed as it was very damaged. I was admitted to St James's Hospital in Leeds, where I spent six weeks. It took me a long time to recover. My parents were told my kidney disease was now progressive, and that one day, I would need dialysis and a kidney transplant.

A family of my own

I left school with no qualifications, so helped my dad who now ran his own shop. I attended regular check-ups at the hospital and was told I would never have children - a devastating shock to me, as I knew I really wanted a family of my own one day.

But less than two years after Mukesh and I were married, in 1990, we were so happy to discover I was pregnant. Our first son was born in 1992, and we were overjoyed at our beautiful boy's arrival. Our second son was born in 1995. Both were healthy and happy, and I am so proud of my sons. As a family we have travelled extensively over the years and my health remained



Far left: Bharti as a child at school. Above: Bharti with her husband, Mukesh

reasonably stable. But in 2022, it was clear I needed to start dialysis, as my kidney was struggling. I now dialyse at the Beeston Dialysis Unit in Leeds. I am on the transplant waiting list and hope that one day I am lucky enough to receive a kidney transplant.

Becoming a peer supporter

My mental health has suffered, and I now see a psychologist who helps me navigate the dark days. Managing kidney disease and life can be a difficult balancing act.

I have always wanted to use my experience, and my love of chatting to people (I speak four languages) to help others facing kidney disease. I really believe it helps to talk to someone who has been through it. So, I am now being trained as a peer supporter so I can fulfil this ambition and know I am really helping someone.

I am incredibly lucky to have my two sons, my supportive husband and would like to say thank you to everyone at Beeston Dialysis Unit for helping me find a positive way to use my experience.



For more information on peer supporters, please go to: https://kidneycareuk.org/getsupport/peer-support/

GET involved!

We receive no funding from the government and our vital services would not be possible without the generosity of our incredible supporters.

£5k tractor and horse races!



When Llinos's daughter, Kate, was diagnosed with kidney failure in early June 2022, she was in the middle of her GCSEs. While under the care of London's King's College Hospital, Kate had peritoneal kidney dialysis for 15 months, until a kidney donor was

found. Her uncle became her donor in September 2023. The retrieval operation took place at the University Hospital of Wales in Cardiff, and the transplant took place at Guy's Hospital in London.

While Kate was undergoing her transplant and ongoing care, her family and friends from her hometown took part in a couple of fundraising events to raise money for Kidney Care UK.

A lively horse race night raised an incredible £3,000 and a Boxing Day tractor run raised £2,400.

A very big, heartfelt thank you to Llinos, her family and friends, and our very best wishes to Kate. *Diolch!*

Thank you!

We couldn't do what we do without our amazing supporters. From bakers to marathon runners and schools to corporates, every penny raised through fundraising events around the UK continues to ensure no one faces kidney disease alone.



Jurassic Coast Challenge

Join 3,000 adventurers of all experience levels and ages and walk, jog or run the spectacular Jurassic Coast – a World Heritage Site. Scan QR code, or go to: https://kidneycareuk.org/kidneycare-uk-events/jurassic-coast-challenge-2025/



Cultural Health Expo London

The Cultural Health Expo will be held at Bridge Park Community Leisure Centre, NW10. The carnival themed event with live music aims to raise awareness of CKD in the black community. Further details from Karen at fundraising@kidneycareuk.org



'Harmony for Hope' concert London

Join The Black
Living Donor Choir for a
soulful Sunday at its World Kidney
Day 'Harmony for Hope' concert
to be held at the Ambassador
Hotel, London WC1H. For tickets,
scan QR code, or go to:
https://kidneycareuk.org/
harmony-for-hope



13-15 JUNE 2025

Great North Swim Lake District

Britain's biggest mass participation swimming event will be back in Windermere and this year you can take part for Kidney Care UK. For details, scan QR code, or go to: https://kidneycareuk.org/kidney-care-uk-events/great-north-swim-2025/

29 AUG 2025

Kidney Golf ClassicBelfast

The Kidney Golf Classic is being held at the Royal Belfast Golf Club, Northern Ireland to raise funds for the charity. Join Stephen Watson and play alongside your favourite sporting celebrities. Pre-booking essential. Scan QR code, or go to: https://kidneycareuk.org/kidney-golf-classic/

Your Amazing London Marathon efforts!

It's not long now until this iconic marathon hits the capital's streets - so we caught up with some of our 156 runners taking part this year hoping to raise over £330k for Kidney Care UK

Carlie's story

Carlie, who lives with nephrotic syndrome, has been receiving lifelong treatment for her condition since being diagnosed at 23. She was inspired to take on the London Marathon in memory of her late father, who was a passionate supporter of kidney charities. Before he passed away, Carlie promised to take on a challenge to honour him -and what better way than the marathon?

Alfie and Alice's story

Alfie, who received a kidney transplant in August 2022 at the age of 21 after living with CKD since childhood, is running the marathon with his girlfriend Alice to raise funds for Kidney Care UK. His journey hasn't been easy-just four weeks after the transplant, Alfie contracted Covid-19, causing his kidney function to

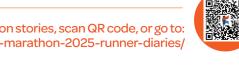
> decline. With the support of his girlfriend, family and kidney transplant team, Alfie gradually regained his strength. His first step toward recovery came when he ran a half marathon just eight months posttransplant. That experience sparked his love for sport again and he now plays for the England Transplant Football Team.

For more London Marathon stories, scan QR code, or go to: https://kidneycareuk.org/get-involved/london-marathon-2025-runner-diaries/



Ashley was inspired to take on the London Marathon after seeing how life-changing a kidney transplant was for his mother-inlaw, who was living with polycystic kidney disease (PKD). Eight years ago, his family received the incredible news that a donor had been found, and watching her recover and thrive has motivated Ashley to give back.

Describing himself as 'very unfit,' Ashley is stepping well outside his comfort zone, starting with 10ks and half marathons as he builds up to the big challenge of this year's London Marathon.







Gala Dinner Titanic Belfast

Your opportunity to shine at a glittering evening of first-class dining and entertainment at Titanic Belfast, all in support of Kidney Care UK. BBC Sports presenter Stephen Watson will host our 2025 Gala Dinner and help us raise vital funds to help people living with kidney disease. For tickets, scan QR code, or go to: https://kidneycareuk.org/kidneycare-uk-events/kidney-care-uk-gala-dinner-2025titanic-belfast/

Great North Run Newcastle upon Tyne

Take on the challenge of the Great North Run the world's largest half marathon, with 60,000

runners coming together each year to conquer its iconic route. For details, scan QR code, or go to:

https://kidneycareuk.org/kidney-care-uk-events/great-north-run-2025/

FEELING inspired...



.BUT CAN'T FIND WHAT YOU'RE LOOKING FOR?

We have plenty of other events to get involved with. Scan the QR code to take a look!





Whatever you do, we're here to support you!



Crafty way to raise money

Arts and crafts fan Orla, seven, and her family, collected an amazing £1,130 for Kidney Care UK

Seven-year-old Orla Ryan from Rotherham is no stranger to fundraising. She and her family have been tirelessly raising money for Kidney Care UK, ever since the family received support from us following Orla's diagnosis of nephrotic syndrome aged just five.

Her nan, Julia, organised a fundraising day last autumn which raised an amazing £1,130 for Kidney Care UK. Local businesses and individuals donated raffle and tombola prizes, and the day included stone painting and lots of baked goodies to buy.

Orla says: "On the day, Kidney Care UK gave us a big cheque with the amount on. I took it to school into assembly and the teacher said, 'You've really made that much?' and all the children were whispering that it was such a lot of money. I think they expected it to be a few hundred pounds!"

Nan Julia is the cook in the family and enjoys baking and cooking meals as part of her fundraising activities.

Carrie, Orla's mum, says: "Orla is very into her arts and crafts, so she makes things to sell. She's going to make some bookmarks, and have a little stall in the summer, and maybe make some bracelets too.

"We're so proud of her. Every day she's a superstar. She gets a bit upset and fed up sometimes, but we always say, 'Have that day, we can feel sorry for ourselves and be fed up, and then we brush ourselves off."

So, a BIG thank you from us to Orla and her family (pictured above with Liz Robinson from Kidney Care UK) for all their hard work, we really appreciate it!



Did you know this year at Kidney Care UK we're celebrating our **50th anniversary**? That's half a century of supporting, advising, campaigning, promoting and representing the kidney community across the UK.

In the summer issue of *Kidney Matters*, we will celebrate our golden anniversary in style!

As always, the magazine will be jam-packed full of the usual fantastic content, but with one difference – this edition will be online only.

This means that instead of receiving your usual copy through the post, you'll be able to access all your *Kidney Matters* favourites via our website www.kidneycareuk.org

In our special anniversary issue, we will be looking back at some of the charity's highlights over the past 50 years and honouring the people who have had the greatest impact over the last five decades.

So for the next issue, due out May 15, why not head over to our website to enjoy your favourite kidney patient magazine!

We will return to our regular print copies, which are sent out in the post if you've signed up for this, plus the online *Kidney Matters* for our autumn issue.









Get in touch to see how we can support you

Call free on 0808 801 00 00

(Monday to Friday, 9am - 5pm)

support@kidneycareuk.org | www.kidneycareuk.org



At Kidney Care UK, we understand the challenges of living with kidney disease, and we're here for you from day one.

Our FREE patient services include:



Financial support



Telephone counselling



Advice and support



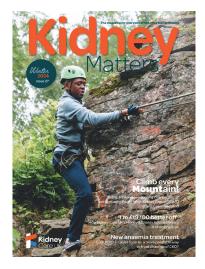
Trusted information



Benefits support



Fighting for better health



New to Kidney Matters or just want to find out more? Keep in touch!

Join our mailing list to receive year-round updates, as well as Kidney Matters magazine direct to your door.



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Phone us on **01420 541 424**



Email **info@kidneycareuk.org** with your name and address, including your postcode.

(Please indicate if you would **ONLY** like to receive a free copy of Kidney Matters magazine).



Clothing, cards and gifts that make a difference

Shop to support our kidney community!

Explore our online shop featuring cards, gifts, clothing and much more.

Featured this month is our **new Kidney Care UK hoodie**, which features the Kidney Care UK logo front and back. With a relaxed fit, this comfy hoodie is designed for everyday wear and available in grey or teal.

Every purchase big or small, will provide vital support to countless families impacted by kidney disease. From badges, keyrings and clothing every item you buy will help raise funds and make a real difference.

Visit www.charitycardshop.com/kidneycareuk



