

KIDNEY LIFE

The magazine of the National Kidney Federation



➤ MY KIDNEYS AND ME

Life, loves and...
swollen ankles!



**New study to explore how well the
COVID-19 vaccination protects
dialysis patients**

Page 04



**Travelling to dialysis
units away from base**

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Welcome to KIDNEY LIFE SUMMER 2021 edition

Hello,

Research can make a big difference in the care of future patients, which is why the NKF are proud to be partnering with Kidney Research UK to fund a study that will look into how well the COVID-19 vaccination protects in-centre dialysis patients – find out how the study is progressing on page 4.

In this issue, we share two inspirational kidney patient stories. Kay Allardyce talks about her life, loves and realising the importance of kidney function (page 14) and John Francis says an emotional thank you to those that have supported him on his journey (page 6).

We also share with you a joint statement issued from professional and patient societies regarding dialysis away from base (DAFB) in the UK (page 16) to help you when considering travel away from home.

Thank you to everyone that has sent in a letter, a story or even a doodle - meet Kevin the kidney bean (page 11). Your contributions and feedback ensure that Kidney Life continues to help meet the needs of kidney patients. As always, please send in your comments – we love hearing from you.

I hope you enjoy this summer edition!

Nichola Rumboll
Editor

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HAVE YOUR SAY
Have you got something important to say?
Do you want to respond to one of our stories?
Share your views by emailing kidneylife@kidney.org.uk

KEEP UP TO DATE

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NKF officers and executive members do usually belong to a KPA, but offer their services to NKF as individuals. As such, NKF recognises that views expressed by its officers and executive members are expressed as individuals and do not necessarily represent the views of their KPA.



HELPLINE **0800 169 09 36**

All **CALLS** to the **NKF Helpline** are **FREE** of charge



Kidney Patient Support Pack: UPDATED FOR 2021

The National Kidney Federation (NKF) produces a Patient Support Pack as a guide for new kidney patients starting their dialysis journey, and we have given it a completely new look.

The pack is for patients who may be facing end-stage kidney failure to help with understanding kidney disease and dialysis and the treatment options available.

The new 60-page booklet is packed full of vital information, including: about the kidneys, fluid balance, anaemia, dialysis treatment choices and useful contact numbers. There are also sections to record your personal information, appointments and renal records.

Our Patient Support Pack has always been very well received by patients, carers and renal nurses and is available free of charge. To request a pack call the **NKF Helpline** on **0800 169 0936** and talk to an adviser or email a request to helpline@kidney.org.uk with your postal address.



HELPLINE
0800 169 0936

Calls to the NKF Helpline are FREE and lines are open Mon - Fri, 9am - 5pm.

DID YOU KNOW?

The **NKF** has been representing renal patients for over 40 years and is the UK's largest provider of kidney-related medical information leaflets, with over 200 titles in our library. Written by nephrologists in simple language for patients and carers, the leaflets are available from the **NKF Helpline** by calling **0800 169 0936** and downloads are available from the 'Patient Information' area of the **NKF** website: www.kidney.org.uk.



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Charity Nos. 1106735 SC049431
Co. No. 5272349 reg. in England & Wales
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Our Helpline is free of charge to call on 0800 169 09 36
The NKF runs the only UK Helpline dedicated to kidney patients, with over 200 unique and regularly updated information leaflets and two fully trained, experienced advisers providing a 5 day a week service to kidney patients, carers and healthcare professionals.

The NKF Helpline is open from 9am until 5pm Monday to Friday on 0800 169 09 36 e: help2@kidney.org.uk



If you want to raise funds for the NKF, plan an event, make a donation to the NKF or discuss leaving a legacy to the NKF please contact Pete Revell (NKF Head of Marketing and Fundraising).

T: 01263 722287
E: pete@kidney.org.uk

New study to explore how well the COVID-19 vaccination protects dialysis patients



We are proud to be partnering with Kidney Research UK to fund a study that will look into how well the COVID-19 vaccination protects in-centre dialysis patients.

This is a landmark occasion for the NKF as this is the first research study we have funded in the charity's history.

As a patient-led charity we see the devastating impact the COVID-19 pandemic is having on kidney patients around the UK. We realised the importance of this study early on and decided it was a must for the NKF to contribute towards it. We're pleased to say that Kidney Wales and several Kidney Patient Associations (KPAs) – Exeter and District, Wessex, South Eastern, Peterborough, and Northamptonshire – have joined us in funding this vital project.

The study will focus on in-centre haemodialysis patients, but we hope to expand the study to include other kidney patients such as home dialysis and transplanted patients over time.



Research teams at Imperial College London and the Francis Crick Institute will analyse blood samples from in-centre haemodialysis patients across the UK before they receive their first vaccination and compare the results with samples taken three to four weeks after both their first and second dose of the vaccine. Scientists at the Francis Crick Institute will analyse the samples to determine how the immune response changes over time.

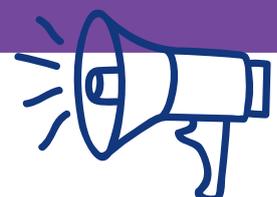
Progress

The study has been progressing smoothly. Samples have been taken from several centres around the UK and the process of analysing them should be quick. The researchers hope to have the first set of data ready in early May.

Going forward

Following the first phase of the study, the hope is to expand the study to other kidney patients to allow for more comprehensive results. To grow the project further we hope more funders will come on board and help us. We'd like to thank the KPAs that have contributed to the fund so far, we hope more will follow soon.

If you'd like to contribute, it's not too late to get involved, you can do so by contacting nkf@kidney.org.uk.



Have you had the coronavirus vaccine?

Jackie Rogers had a kidney and pancreas transplant in September 2008. She tells us all about going for her second vaccination at Canterbury Cricket Ground.

It was like a military operation and everyone there was a kidney patient. I might actually call the hospital to see how many they did on that day. It was an amazing feeling of empowerment.

I'd never seen so many fellow patients in one place. We shared stories of dialysis, transplants, shielding, but there were two constants: we were all so lucky to be alive especially those of us who have had transplants, and the sheer joy of being able to have our second job.

We had to queue for a while, outside!! It wasn't great but we were grateful. When we saw a vulnerable patient, wheelchair or frail, we let them jump the queue. We'd all been in that situation before and we were one big renal 'family'.

We checked in as before, but this time had to join another queue, then after a little while about 50 of us were called in. We went upstairs where I went before. Chairs were in a line and someone came and checked our cards. Then another came and asked all the questions. Then a doctor came and asked some more... it was one of my consultants – I hadn't seen her for ages. Every time I see her I tell her she saved my life (10 years ago I got rushed in very ill and thankfully she was still on site and put a central line in, my BP 70/50 and super dehydrated, it was touch and go whether I would lose my transplant).



Then a nurse and healthcare assistant came, checked my details and administered the vaccine. I didn't feel anything. I waited 15 minutes and drove home.

It was like a conveyor belt, super-efficient and a brilliant atmosphere. And no side effects!

“

It was like a military operation, all renal patients. I might actually call the hospital to see how many they did on that day. It was an amazing feeling of empowerment.

”

SAYING THANK YOU TO THOSE THAT HAVE SUPPORTED ME

By John Francis

Definition of kidney transplant: The transfer of a healthy kidney from one person into the body of a person who has little or no kidney function. I fell into the latter of these two categories.

I was working away as part of a public house relief management team – my wife Debbie and I started this job some 12 to 18 months before I got the call that changed my life.

We were both enjoying work and life immensely when one day I felt quite unwell. After a blood test and a visit to a local GP's surgery, I was told in no uncertain terms to get myself home as a bed had been booked for me in Winchester Hospital.

And so began the transplant journey.



Saying thank you

Before I go any further, I must take this opportunity to say thank you.

Firstly, to my wife Debbie, because to be honest, I would not have made it this far without her. She is and always will be my rock, the love of my life and my soul mate. We have been through some stuff in our 30 years of marriage and, most of that stuff has been medically orientated.

The stories I have could fill a book – the people we have met, the doctors, nurses, and patients, past and present, the mishaps, the hard times and the many good times we have shared. Debbie, I love you and thank you so much for being you.

I must also thank the NHS - where do you start with the NHS? They are just brilliant, clever, dedicated and kind people. Dave, the guy who taught us how to use a dialysis machine, Lucy, who drew faces on my toes while I was in bed at Portsmouth Hospital, the doctor who told Debbie off because I missed an appointment (he was such a lovely guy) and it was all my fault, sorry Debs again, and the many other people that I haven't got space to mention.

Most of all my thanks go to the individual, or family of the individual, who gave me the gift of life and made the brave decision to donate in such a difficult moment. Every year, this being my 29th year as a transplant patient, I say a prayer and give thanks for what you did for me. I cannot express in words my feelings of gratitude - to be able to live, have kids and have a full life – it is all thanks to you, bless you.

“

Writing this, I am crying. Thank you whoever you were, thank you Debbie and thank you to the NHS.

”



Putting life into perspective

My medical issues have given me a very matter of fact way of looking at life. For example... A guy came into a bar, 'Hello Pete, what a day I have had. Woke up to a flat tyre, the wife was moaning and when I got to work the boss was in a foul mood'.

From my point of view, things of this nature are minor inconveniences. Major illness is a life-changer and it puts your life into perspective. A blown tyre, a dropped plate or a missed bus, never mind, just be thankful for being here in the first place.

I only dialysed for 15 months – regular trips to Portsmouth, three times a week for six-hour sessions. And then, once Dave had instructed us on how to use the machine, we moved to Basingstoke and self-dialysed. It was a good move, saving us at least two hours a session.

I was an HGV driver and I could not work so I went back to college and embarked on a City and Guilds Motor Mechanics Level 1 and 2. One morning, I was about to leave for college and the phone rang, "Mr Francis?" asked the caller.

"Yes, speaking," I said.

"We have a kidney for you, can you get to Portsmouth as soon as possible?" I was asked.

"Yes, I'll be there." I cried.

I made a call to Debs, "Portsmouth just rang, they've got a kidney." We cried.

After my transplant, my kidney did not work for over 35 days. On the morning of day 40-something, Debbie and I were on the ward and cleaning down the dialysis machine to dialyse when my surgeon popped his head through the door and exclaimed..."You can forget that. It's working!"

My surgeon was a lovely guy, dry sense of humour, with yellow fingers due to the amount he smoked. He shut the door and walked away. We cried, again.



So, from 30 years ago and dialysing three times a week, marriage on hold, not working... to present-day and coming out of lockdown number three – feeling very unsure and anxious about getting back to life again. I have spent 13 months shielding but feel so lucky that I am still here when so many have lost loved ones.

I have had my first job and by the time this is published, I will have had my second. I guess we need to get back to normality and some sort of regular life. I've made changes in my life before and if I must make changes again, I will. I have a gorgeous wife, three fantastic children and grandchildren, and we're making cautious steps back into the world with so much to live for.

Writing this, I am crying. Thank you whoever you were, thank you Debbie and thank you to the NHS. It still makes me emotional and probably always will.



^ All smiles – John and wife Debbie

GET INVOLVED

There are many ways you can make a difference and raise money to support kidney patients across the UK.



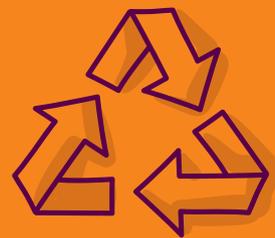
WATER CHALLENGE

Thank you to everyone that took part in the challenge! We are collecting the sponsor money and will reveal the grand total in next months *In Touch* newsletter. Please email nkf@kidney.org.uk to receive *In Touch*.

DON'T TRASH IT, CASH IT!

We all know the benefits of recycling... So, if you have unwanted items, send them to us!

We have enclosed a recycling envelope in which you can donate unwanted goods including jewellery, watches (any material, damaged or broken), currency (coins or banknotes, UK and foreign), mobile phones, cameras (old film, digital and video) and lots more!



Got a question? Call 0800 633 5323 or visit www.kidney.org.uk/recycling



2021 Spring DRAW

Are you a lucky winner? The draw took place on Weds 8th May and all the winners are published on our website:

<https://www.kidney.org.uk/nkf-draw>

BEST FOOT FORWARD

Can you step up to the 'Best Foot Forward' challenge in June?

Sign up now and walk or run 60,000 steps – representing the 30,000 people on dialysis and 30,000 people transplanted – over the entire month of June, across a week or even a day.

Email nkf@kidney.org.uk to request a fundraising pack.

SIGN UP
NOW



FUNDRAISING

Fancy getting involved in one of our fundraising events?

Check out www.kidney.org.uk to see the full selection. And, if you fancy taking part in an organised run (anywhere in the UK) we can secure your place. For details of events or fundraising in general contact Pete on 01263 722287 or email pete@kidney.org.uk

Ken Tupling:

10 MAY 1941 – 12 FEBRUARY 2021

Ken sadly passed away, aged 79, after contracting COVID-19 whilst in hospital being treated for pneumonia.

A proud Yorkshireman, Ken lived all his life in Rotherham. He was educated at the local grammar school and spent most of his working life as a cashier/accountant. He was married to Margaret, had two sons, Andrew and Christopher, and four grandchildren.

Ken was an enthusiastic sportsman in his younger days. He played table tennis, cricket and refereed football at grassroots level, and later took part in table tennis, bowls and snooker at several Transplant Games. He was also a keen Rotherham United supporter.

Having taken blood pressure pills for over 20 years, Ken was only diagnosed with PKD after changing his GP practice. He was referred to Sheffield Kidney Institute in December 1991 and started CAPD three months later.

Ken was fortunate to receive a cadaver transplant after only 13 months of dialysis, on 16 April 1993. He was hugely grateful for his transplant and always fiercely protective of it, convinced it would never fail – it didn't and was still going strong after almost 28 years.

Ken became very involved with his local Kidney Patients' Association (SAKA) and the NKF, serving as its co-chair with the late Ray Mackey and more recently as National President. His work for fellow patients included him attending European patient conferences; he spoke to pharmaceutical companies in France and Switzerland about the vital importance of their drugs; he helped form the All-Party Parliamentary Kidney Group; he served on the British Transplant Ethics Committee; he was a patient representative at the National Institute for Health and Clinical Excellence (NICE) and provided a patient's perspective on research undertaken by renal specialists at Sheffield, Leeds and Keele Universities. Just as importantly he was always ready for a chat and/or word of encouragement with fellow renal patients.

Ken maintained that he got more out of his 'work' than he put into it, but the sympathy cards and letters Margaret has received bear witness to how highly he was regarded.

Ken now lies at rest in the village churchyard at Whiston, Rotherham where he worshipped and was a chorister for many years.



Ken was a keen sportsman and a lifelong Rotherham United fan

Ken became very involved with his local Kidney Patients' Association (SAKA) and the NKF, serving as its co-chair with the late Ray Mackey and more recently as National President.



A transplant surgeon's perspective

OPT-OUT

By Jeremy Crane

As a transplant surgeon, I am often asked, not just by patients, but also by friends and family, about the opt-out system for organ donation that came into effect last year and how it will affect the transplant program in the UK.

The UK organ donation programme used to be an opt-in system, which is where someone is not considered to be an organ donor unless they sign up to the Organ Donor Register. However, as of 20th May 2020, the UK organ donation programme changed to an opt-out system, also known as Max and Keira's law. This is where all of us are considered to be an organ donor (with some exceptions e.g. under 18s) unless the person specifically requests not to be on the Organ Donor Register, in other words, they 'opt-out'. It is also known as 'deemed consent'.

The law was changed from opt-in to opt-out because sadly, there are always more people waiting than receiving a transplant and so this change in the law would be a way of increasing the number of donors. But will it have the positive effect we all hope for? One way of trying to work this out is to look at one of our European neighbours, Spain. They boast the highest rates of deceased donors in the world. Like us, they changed to an opt-out system and they did this back in 1979. But looking at Spain, what is interesting was that it took about a decade after opt-out was introduced for the rates of donation to rise. So why wasn't there a significant change within the first decade when the law came into effect? The reality is that no one is really sure, but from 1989 onwards there was an obvious positive change, and it is clear that what happened in 1989 is something the UK should learn from.

So, the important question is, what happened in Spain in 1989 that didn't happen in 1979? Well, new laws came about in Spain, one of which was for there to be a transplant coordinator in every hospital that could identify all potential donors in advance. This was not associated with any financial incentive for the hospital. Also, making family wishes part of the process of organ donation, and working with families very closely was made key. This family involvement was encouraged in every way possible. There were also close working ties with the media and journalists with the overall aim of creating 'a positive social climate for donation.'

No one knows how the new law will affect the UK's transplantation programme, but a way of trying to find out what might happen is to look at what happened in Spain after their opt-out was introduced. Looking at Spain's statistics it stands to reason that if we want to emulate the fantastic rates of organ donation that Spain boasts, we need to copy their ways of making organ transplantation into a positive culture. So over and above deemed consent, we need to put in place other measures, like Spain did, to create positivity surrounding organ donation. The actual 'opt-out' system itself might not have the positive effect on deceased organ donors that was originally thought. However, the law coming into action might have the added benefits of raising awareness and creating conversations about organ donation. It is these benefits that might boost numbers, more than the opt-out itself.



What is crucial is that we have organ donation conversations and share our decisions with our families and loved ones.



When discussing this topic I am also asked, 'If I don't opt out, will my organs be automatically taken?' The answer is a definite no! Your family will always be involved before donation takes place, so it's important for all of us to share our wishes with our families and loved ones. That will mean your decision is clear and your family can have peace of mind knowing your decision is being honoured. What is also important is that your faith and beliefs will also always be taken into consideration before organ donation goes ahead.

Organ donation in the new 'opt-out era' can potentially affect anyone. What is crucial is that we have organ donation conversations and share our decisions with our families and loved ones. Then, they are clear as to what we want and can honour our wishes.

Jeremy Crane MD FRCS (vasc)

Consultant transplant and vascular surgeon based at the West London renal and transplant centre at the Hammersmith Hospital.

Keep in touch

@JeremyCraneMD

www.transplantandvascular.com

READER'S letters

OVER TO YOU



Dear Kidney Life.

Like many dialysis patients, I read your magazine with continued interest. I have been on dialysis for just over two years and under the exceptionally good care of the renal team at Queen Alexandra (QA) Hospital in Portsmouth.

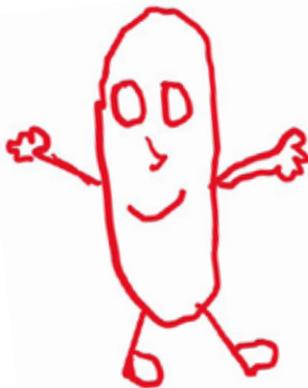
Whilst I do from time to time have treatment in the hospital my usual venue is the Havant Dialysis Centre. I have nothing but high praise for the consultants, doctors, nurses and carers whose professional skills and kindness is exceptional and consistent. I was well prepared by the team to begin dialysis and although a big shock to the system initially things have settled down into a well-worn routine with of course a few bumps in the road.

The one matter that I think is worth sharing with you and your readers is the impact dialysis can have on your general health and wellbeing. One of the side effects I suffer is the odd day of wooziness and serious balance problems. One or two other patients say they have migraines and suffer low blood pressure following dialysis. I am sure there are other ill effects experienced by others and it would help if patients were given literature that explains the possible side effects when starting dialysis at the hospital or indeed carrying it out in their own homes. All prescription medication carries detailed information about the medicine and the possible side effects and giving dialysis patients this information would increase understanding of the process going forward.

May I end by saying a big thank you to the renal team at QA and the dialysis teams at both Havant and QA - especially during the last year as we have struggled to come to terms with COVID-19.

Yours sincerely

Brendan Gibb-Gray



Dear Kidney Life.

As a practising haemodialysis patient at Welshpool renal unit, I appreciate that kidney disease is a profoundly serious issue and often a depressing one, and I just wanted to suggest that it might be helpful to inject a little bit of humour into the magazine by way of either some very simple cartoons or cartoon characters, which can be a useful vehicle for getting messages or information through to patients...

...The reason that I have made these suggestions, is that when I started on haemo three years ago, I was rather frightened and indeed incredibly bored sitting for four hours at a time. To counter these problems, I started doodling and trying to teach myself how to draw cartoons, as best I could, whilst connected to the machine. It turned a somewhat miserable experience into a thoroughly enjoyable one and it has kept me happily amused for hours on end.

For what it is worth, I have attached 'Kevin the Kidney Bean', a two-minute doodle I prepared yesterday, whilst thinking about these suggestions.

Yours sincerely

Robin Sorrell



Have you got something important to say? Do you want to respond to one of our letters?

HAVE YOUR SAY

Share your views by emailing kidneylife@kidney.org.uk

KPA Day

2021 ROUND-UP: YOUR VOICES HEARD

Over sixty Kidney Patient Association (KPA) members along with kidney patients from across the UK, joined us on Saturday 27th March for this year's 'virtual' National Kidney Federation KPA Day.

The annual event, which included the National Kidney Federation AGM and council meeting, heard from leading voices in the renal world and allowed fellow KPA members to reconnect and share their voice about the experience of kidney patients over the past year.

The day began with a warm welcome from NKF chair, Jim Higgins, and attendees then heard from the first of two speakers, sharing an insight into the treatment and care of kidney patients throughout the pandemic.

COVID-19 ON THE DIALYSIS WORLD

Consultant nephrologist, **Paul Cockwell** provided an insight into the impact of COVID-19 on the dialysis world. He spoke about the rapid response of the renal community and professionals coming together early in the pandemic to form a national collaboration – he praised their work as they continue to navigate a way forward.

He shared data that considered the disproportionate impact of COVID-19 on in-centre dialysis patients when compared to those patients receiving dialysis at home. And he spoke about the importance of vaccination as the way out of the pandemic for people with kidney disease. He ended with a plea that we must all encourage people to get vaccinated.

NKF AGM

Jim Higgins, NKF chair, praised the work of the NKF over the past year. He highlighted the development of the NKF five year strategy as a significant and positive step for the charity and the ongoing importance of fundraising.

The 2021 National Kidney Federation AGM followed and the next NKF officers and executive committee members were elected as follows:

OFFICERS

Chairman – **Jim Higgins** – Northamptonshire KPA

Vice-Chairman – **Brian Child** – North East KPA (NEKPA)

Secretary – **George Palmer** – Exeter & District KPA

EXECUTIVE COMMITTEE MEMBERS

Ros Aird – Lister Area KPA

Glynis Beattie – Sheffield Area Kidney Association (SAKA)

Phillip Beattie – Sheffield Area Kidney Association (SAKA)

John Burdett – Northamptonshire KPA

Caryl Bryant – Royal Free KPA

David Coyle – Manchester Royal Infirmary KPA

Sarita Khurana – West London KPA

Tarsem Paul – Lister Area KPA

Nii Plange – Royal Free KPA

Michael Sinfield – Six Counties KPA

John Roberts – Hope KPA

The NKF are pleased to report that **Kirit Modi** will continue as **NKF honorary president**.

THE IMPACT ON KIDNEY DONATIONS AND TRANSPLANTATION

Rommel Ravanan, Chair Kidney Advisory Group, NHSBT spoke about the impact of COVID-19 on kidney donations and transplantation, and provided an update on the new strategy for organ donation and transplantation.

He spoke about the impact on services during the peak of the Covid waves and explained how specialist resources were relocated to work elsewhere in the NHS, and how many hospital theatres became ICU wards or were converted into something else.

He explained that despite unimaginable pressure, at no time did transplantations stop completely in the UK.

Next, the NKF council meeting took place and the day drew to a close.

FIND OUT MORE

The annual KPA day is an opportunity to connect with KPA members from across the UK and is a chance to influence therapies, services and treatments provided to kidney patients. If you want to find out more about your local KPA or register your interest to attend next year's event please get in touch: nkf@kidney.org.uk



◀ Rommel Ravanan

◀ Paul Cockwell

SAVE THE DATE!

Our annual patients' event is back – and will take place on Saturday 9th October 2021.



Due to the pandemic, we took the difficult decision to cancel last year's event but we are pleased to announce that this year we will be holding a virtual event.

As usual, we will have lots of information about the kidney world and there will be opportunities to talk with other kidney patients and nephrologists.

Keep checking our website and social media for information on how to register.

www.kidney.org.uk  [@KidneyNKF](https://www.facebook.com/KidneyNKF)  [@NKF_UK](https://twitter.com/NKF_UK)  [@nkf.uk](https://www.instagram.com/nkf.uk)



MY KIDNEYS AND ME

By Kay Allardyce

Kay Allardyce had never considered the importance of kidney function until, aged 24, she was told she had high blood pressure and a kidney disorder. She tells us about her life, loves and... swollen ankles!

Back in 2007, I travelled by plane to a wedding in Naples, Italy and like most weddings abroad, it was hot. The wedding involved lots of eating (seven courses in fact!), drinking and sitting, and I noticed that my feet and ankles felt tight in my strappy shoes – uncomfortable as women’s shoes are anyway, but doubly so due to the swelling.

A couple of weeks later and the swelling was still there. I would wake after a night’s sleep to feel them slightly improved, but they typically stayed ‘puffy’ and massage and elevation didn’t seem to help. I had recently finished a degree in osteopathy where you are taught about many conditions and when certain signs and symptoms may need further investigation. I had a feeling that something quite serious was up.

Eventually, I went to my GP and she immediately referred me to the hospital. My blood pressure was sky high – yet another eye-opener at just 24 years old.

I was diagnosed with focal segmental glomerulosclerosis and my kidneys were not filtering blood as effectively as they should. Not only was my blood pressure high, but I had been leaking large quantities of protein and was placed on warfarin to help with the clotting factor in my blood. This, along with blood pressure medication helped to stabilise my health, for a while.

So, for the next five years, I focused on my career as an osteopath. I grew my list of patients and I qualified to teach Pilates. Over time, my energy levels began to waver, and by the evenings I found myself shattered, especially if I had taught a couple of Pilates classes after treating patients all day.

In 2010, I took a three-month sabbatical and travelled around Australia. I felt a strong urge to fill my life with experiences - perhaps subconsciously due to the kidney disorder, and if or how long it would be until my kidneys deteriorated to the point of needing dialysis or a transplant. I tried not to ponder it, instead, I filled my life with travel, skydives... and love!





LOVE, LOSS, AND A NEW LEASE OF LIFE

By the time my kidneys deteriorated to below 20% functioning I was with, my now-husband, Tim. We experienced an unexpected miscarriage – my menstrual cycle was sporadic and I assumed my fertility was low. It was a mistake that left me with a large loss of blood and I was lucky not to have a transfusion. I took time off work and regained my strength.

Five months later I found myself preparing for a transplant. My Mother, aged 58, was in good health with good working kidneys. She was a very good match and keen to donate one to me. In her own words, “Well Kay, I brought you into this world, I am going to keep you here!”. On 30th October 2012 at Guy’s Hospital, I had transplant surgery. It took some weeks for my Mother’s body to adjust to the loss of a kidney, whilst my kidney started working straight away. The surgeon was extremely pleased, as were we.

My health seemed to flourish and the energy I had gained was remarkable. So much so, Tim and I started bike riding and training and we decided to cycle from London to Paris to raise money for GSTT Charity. In May 2013, we departed from outside Guy’s Hospital (six months post-transplant) and we cycled unsupported for 3.5 days arriving at the Arc de Triomphe in Paris! The ride was a thank you for all GSTT had done for me and to celebrate the memory of Tim’s Dad who had passed away that year and had wanted to do the cycle challenge himself.

Thumbs up from Kay –
about to start her first vaccination shift



PREGNANCY AND KIDNEY DISEASE

Now, with a functioning kidney, I was keen to start a family and I began pre-pregnancy counselling at Guy’s. This was excellent, very informative and personalised to my condition and my health.

And just under three years following my transplant, we had our first child, George. I had been diagnosed with pre-eclampsia and after the initial stage of induction my labour started and he came naturally. We had trained in hypnobirthing and using simple breathing and mind exercises I managed to give birth without the need for drugs.

I adored being pregnant, the most special times were during the scans and seeing him snuggled up next to my Mother’s donated kidney sitting in the lower pelvis. Without this, he could not have been born.

Two years later and Rosealin was born – four weeks premature, due to the diagnosis of pre-eclampsia again. I revised the hypnobirthing skills and give birth naturally. This labour was quite a bit quicker!

The children are now aged five and three, and although my kidney function has taken a little dip this was expected after having children.

Life is busy, and I continue to enrich it, focusing on the simple stuff and making memories with loved ones. I work part-time as an osteopath and Pilates instructor and I was recently deployed to administer the COVID-19 vaccinations as part of the national vaccination programme. I feel lucky to have received my vaccination.

What next? I’m all set to complete a sponsored abseil down St Thomas’s Hospital that was unfortunately postponed due to the pandemic – I’m hopeful it can be rescheduled for September this year. Oh, and I’m also writing a book about my kidney experience so far.

And the swelling? I continue to be well and there’s still no puffy ankles!



TRAVELLING TO DIALYSIS UNITS away from base



NEW UK GUIDANCE ISSUED TO HELP KIDNEY UNITS SAFELY ADMIT VISITING DIALYSIS PATIENTS

As COVID-19 infection rates drop across the UK and the government has published its proposed roadmap out of lockdown restrictions, patients are keen to make plans for holidays.

Patients receiving dialysis remain clinically extremely vulnerable to COVID-19 compared with the general population and transmission has occurred in dialysis units. The guidance recommends that dialysis away from base (DAFB) should be discussed on an individualised basis between the patient and their clinical team using the principles stated adjacent.

This advice applies irrespective of the DAFB type (Haemodialysis or Peritoneal Dialysis) and the **guidance only applies if shielding or local lockdown is not in place in base or destination units.**

Information on incidence of new COVID-19 infections in UK dialysis units can be found on the latest **Renal Registry report** [link: <https://renal.org/audit-research/publications-presentations/report/covid-19-surveillance-reports>]



HERE IS THE NEW GUIDANCE AND WHAT UNITS WILL BE CONSIDERING BEFORE YOU TRAVEL:

- 1 Assess risk based on the current incidence of COVID-19 in the base unit/locality and the designated unit/locality for DAFB.
- 2 Ensure that there is a documented discussion between the clinical staff at the base unit and the DAFB centre for shared awareness of COVID-19 rates and confirmation of number of recent COVID-19 infections in the base unit or receiving service. Ensure that the patient is aware in advance of the local protocols that they will need to follow.
- 3 Those wishing to have holiday dialysis should have received 2 doses of COVID-19 vaccine separated by at least 3 weeks before travelling. Travel should ideally be at least 2 weeks after the 2nd dose to build up an immune response. However, if a patient has refused vaccination or been unable to be vaccinated this should not exclude them being considered for DAFB.
- 4 Patients should have a negative PCR COVID-19 swab 3-5 days before travel.
- 5 On return to the base unit, patients should dialyse in isolation for 2 weeks, and have COVID-19 tests as per unit protocol. The base unit should consider its capacity to isolate patients on return from holiday whilst planning the timing of patients' holidays.

- 6 Patients should not travel if they are in close contact (within 2m distance for at least 15 minutes) of any individual with COVID-19 infection, including other patients on the dialysis unit, within the preceding 14 days. Or been advised to self-isolate for any reason.
- 7 Patients should not travel if they have symptoms of COVID-19 or are awaiting a COVID-19 PCR test result.
- 8 Patients should not travel if they have planned surgery within 14 days after the proposed holiday return date as they will be asked to self-isolate for 14 days before the operation.
- 9 Patients should follow the local guidance for high-risk prevalence, in the DAFB locality. This guidance is likely to vary with time and between areas.

- 10 Advise patients to take out travel insurance before making any bookings due to the risk of sudden cancellations. Check what is covered by travel insurance in the event of an infection with COVID-19 just before or during the holiday.

Visit the NKF website to read the joint statement (in full) from professional and patient societies on dialysis away from base (DAFB) in the UK
 [link: <https://www.kidney.org.uk/news/new-dialysis-away-from-base-guidance>)]

Additional resources

NKF website holiday advice section
<https://www.kidney.org.uk/holiday-guide-for-kidney-patients>

Job Vacancy

LIAISON OFFICER

Job Title: Liaison Officer

Responsible to: Chief Executive

Location: NKF HQ, Worksop, S81 8BW, working from home will be considered. UK wide travel required.

Salary: Negotiable, dependent on experience, knowledge and qualifications.

Hours: Full time position, part time would be considered.

Benefits: Generous holiday allowance and pension.

The National Kidney Federation's mission is to improve the quality of life of kidney patients and their families across the UK. The charity is a unique place to work because the NKF is the only national kidney charity run by kidney patients for kidney patients.

Following the completion of our new strategy, the charity is embarking on an exciting new phase of growth. We are looking to recruit a new member of the team to commence the position as NKF Liaison Officer.

We would like to appoint a person who is able to:

- Develop and maintain contact with all Kidney Patients' Associations (KPAs) affiliated or not to the National Kidney Federation.
- Co-ordinate support for KPAs who require help from the NKF.
- Help set up a KPA in areas where there is no KPA presence.
- Develop & maintain contact with all Trusts providing Renal Care & Renal Commissioning Groups.
- To set up agreed systems and procedures to assist KPAs with their negotiations with Health Authorities and Hospital Trusts concerning Commissioning and other patient issues.

Skills required:

- Empathy with kidney patients and the problems they face is essential.
- Knowledge of how a charity works is desirable.
- Stakeholder engagement experience essential.
- Excellent communication and negotiation skills.

A full job description and person specification are available by request via the NKF website <https://www.kidney.org.uk/nkf-job-vacancies>

To apply for the role please send your CV and a covering letter explaining the reasons you should be considered for the role to:

nkf@kidney.org.uk

If you would like any further information, or for an informal chat, please call 01909 544 999.





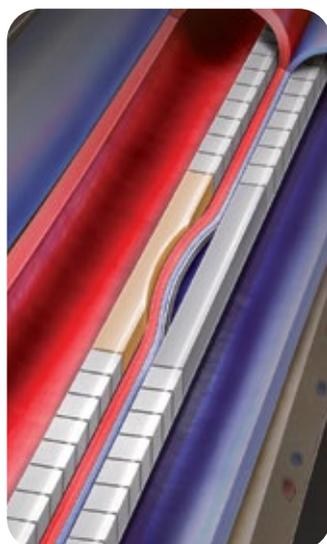
FOCUS ON: the Endovascular Arteriovenous Fistula (EndoAVF)



Article by Ounali Jaffer

I have had the privilege of working as a Consultant Interventional Radiologist for the last eight years at Barts Health NHS Trust which has one of the largest haemodialysis populations in the country. Some of you may be unfamiliar with the term 'Interventional Radiologist' but I suspect a few of you have encountered one of us in your care. We perform minimally invasive procedures using x-ray guidance. Essentially, much like surgeons, we are plumbers but we don't use a scalpel and we leave no scars!

I have been fascinated by kidney disease since my medical school days. In the early part of my training, one of my close relatives became quite unwell and required haemodialysis. I understood early on that the fistula was his lifeline and there were a finite number of options in creating one, so maintaining the fistula for as long as possible was crucial. When we learnt there was a problem with the fistula due to an internal narrowing, naturally we worried. The fact that he was able to go and have a simple day case procedure that restored the fistula to its former glory fascinated me and as they say, the rest is history.



ENDOVASCULAR PROCEDURES

Minimally invasive procedures using x-ray guidance is a relatively new kid on the block in absolute terms of medicine but in reality, has been around for the last 50 years. One of the terms used for this type of operation is endovascular procedures, performed using a pinhole access point into the veins and arteries leaving minimal or no scarring for the patient. As the procedures are minimally invasive, the stresses on the body are less than open surgery and as a result, most procedures can be performed as day case operations.

Recently we have seen an innovation explosion for patients with end-stage kidney disease, with many new devices becoming available. New types of balloons coated with medicine, as well as stent-grafts have allowed us to treat narrowings in arteries and veins much more effectively. These are exciting times for endovascular treatments and it is nice to report that many centres in the UK are shaping the development of these technologies through their research programs.

EndoAVF

One of the latest innovations has been the *endovascular arteriovenous fistula* (EndoAVF).

Traditionally, an arteriovenous fistula is formed in the arm by surgically connecting the artery to a vein. The vein is then used after maturation to cannulate with needles to enable haemodialysis. The EndoAVF is an entirely minimally invasive procedure, so no surgical incision and no surgical scar. A real advantage is that it adds another option for patients as the site used to form the fistula is within the upper forearm, which differs from traditional open surgical procedures.

Within the UK, the system used is called the WavelinQ EndoAVF. The data that has come out so far on the device has been very promising showing high success rates of fistula maturation and very low reintervention rates. Compared to traditional surgery, wherein as many as two-thirds of cases the first attempt may fail, this early data is very encouraging.

Much like most endovascular treatments, entry is through pinhole access points into the vein and artery, either at the wrist or just above the elbow. Dye is then used to map a path to the preferred site of fistula formation, followed by a thin wire into both vessels. Using x-ray guidance, small tubes containing magnets are then advanced into both the artery and vein. When the magnets are perfectly aligned, they will connect which then brings the vessels together. A radiofrequency pulse is then emitted for a fraction of a second and a channel is formed between the artery and vein with the heat applied ensuring a tight seal between the blood vessels. The magnets, tubes and wires are all removed through the access points and the procedure is complete with no stitch required. The procedure is carried out under local anaesthetic and in my personal experience, the procedure takes approximately 30 minutes. As a result, it is entirely feasible that a patient could come in the morning and be home by lunchtime.

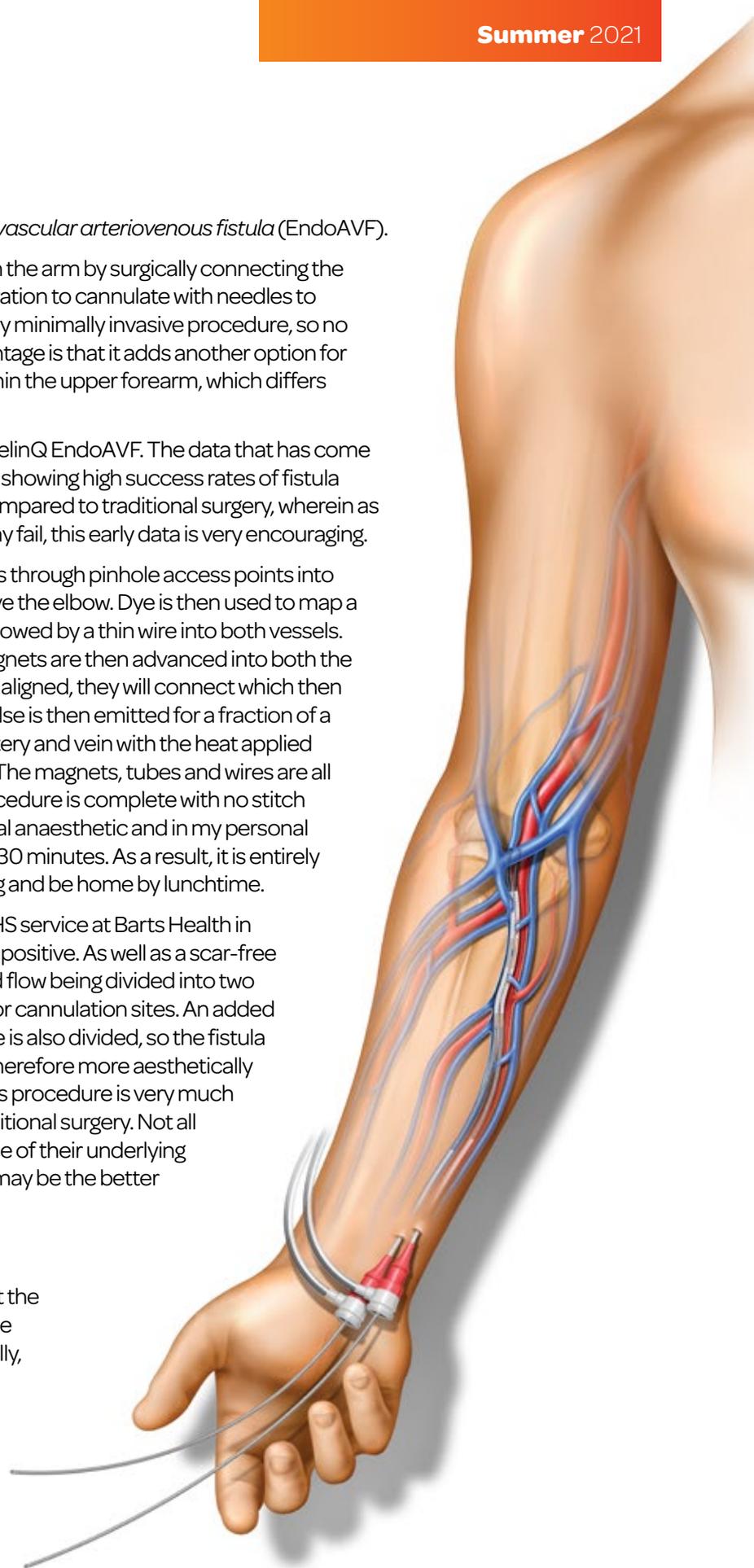
We were the first to offer the procedure as an NHS service at Barts Health in 2019. The feedback from patients has been very positive. As well as a scar-free result, we have found that as a result of the blood flow being divided into two usable veins for dialysis, we have more options for cannulation sites. An added advantage of the divided flow is that the pressure is also divided, so the fistula is usually much less prominent on the arm and therefore more aesthetically pleasing. It is important to note, however, that this procedure is very much an adjunct as opposed to a replacement for traditional surgery. Not all patients will be eligible for this procedure because of their underlying anatomy and in some cases, traditional surgery may be the better option for the patient.

THE FUTURE

EndoAVF is gaining wider recognition throughout the UK, with some centres starting to offer the service and many more showing a keen interest. Hopefully, having this safe and effective option available to patients throughout the UK will soon become a reality. Whilst these remain early days, the results have been encouraging and having another option to avoid the complications associated with dialysis lines is something we are all glad to have.

I hope you all stay safe.

This article was developed by the respective author, and the findings, interpretations, and conclusions contained or expressed within them do not necessarily reflect the views of BD





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World Kidney Day 2021



Thank you to everyone who took part in this year's World Kidney Day!

The theme for this year was to highlight how Covid-19 has impacted people with kidney disease as well as advising people how they can reduce their risk of developing kidney disease.

As part of the Kidney Charities Together Group we ran a successful photo competition, and the winner received £250 in Amazon vouchers.

Congratulations to Rachel, who sent her image to us via Instagram (@coorie.designs).



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PUZZLE

Keep your mind active and improve concentration... Enjoy!



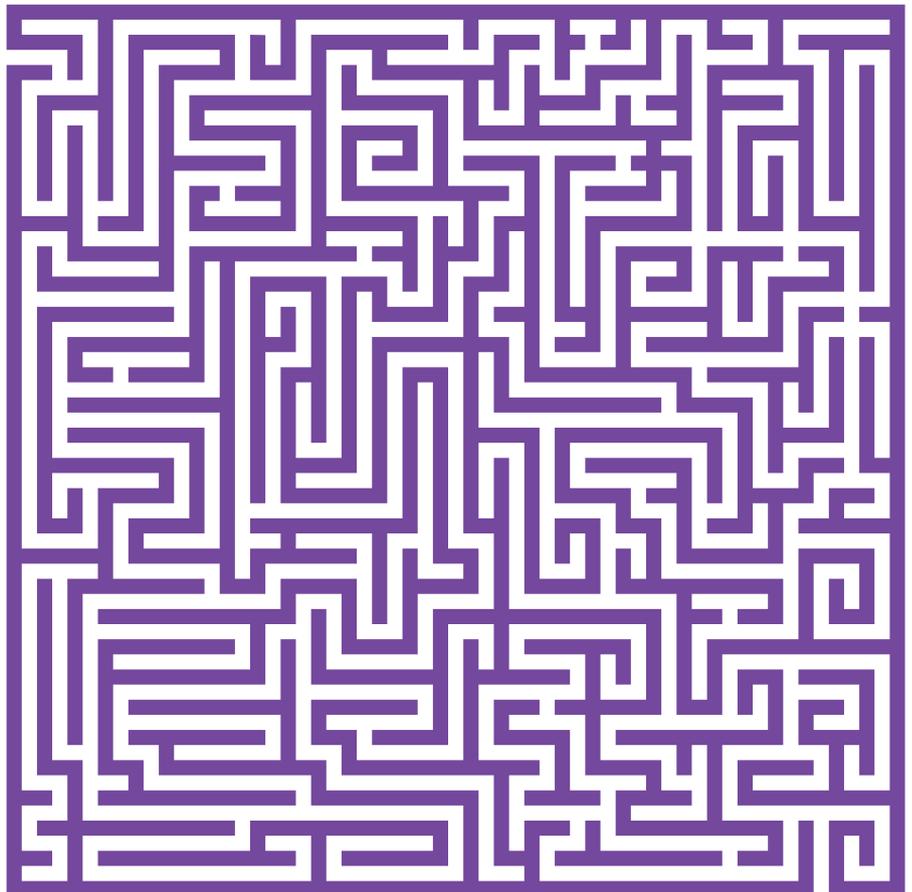
SUMMER WORD SEARCH

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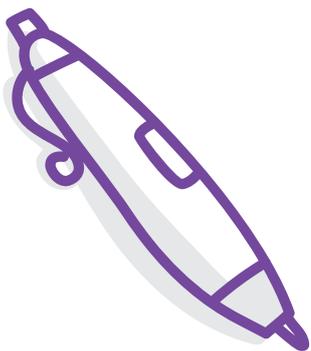
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- ICE CREAM
- LEMONADE
- SPRINKLER
- SUN CREAM
- BEACH
- SIGHTSEEING
- SHORTS

Which of the listed words is missing from the word search?

ENTRANCE 



AMAZING MAZE



EXIT 

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Walk **60,000 steps**
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vital funds for
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To register please email: nkf@kidney.org.uk with your name and address and we will send you a fundraising pack.

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Registered Office: The Point, Coach Road, Shireoaks, Worksop, Nottinghamshire S81 8BW

Telephone: **01909 544 999** • Email: nkf@kidney.org.uk • Helpline: **0800 169 09 36** • Website: www.kidney.org.uk

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WE NEED YOUR SUPPORT

The National Kidney Federation (NKF) relies entirely on your support and donations to continue its vital work supporting kidney patients and their families.

A regular donation from you will help support every kidney patient in the UK

- £20** Helps us with printing and postage costs to distribute our free of charge Helpline leaflets
- £10** Helps towards our campaigning to increase patients on home dialysis
- £5** Helps us make Government changes in Parliament
- £2** Covers the cost of your Kidney Life magazine

WAYS TO DONATE:



Donate by phone

You can call us on **0800 169 0936** for a chat and to make a donation.



Donate online

Or visit www.kidney.org.uk/donate



Donate by post

I would like to donate a one off regular monthly payment of: £5 £7.50 £10 Other

Preferred collection day:

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I enclose a cheque*: *Please make cheques payable to: National Kidney Federation

If you are a UK taxpayer your donation will be worth 25% more at no extra cost to you.



Yes - I am a UK taxpayer and would like to Gift Aid my donations now and in future. I understand I must pay enough income tax and/or capital gains tax each tax year to cover the amount of Gift Aid that all charities and community amateur sports clubs claim on my donations in that tax year, and I am responsible for paying any difference. I will inform you if my tax status, name or address change or if I wish to cancel my Gift Aid declaration.



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