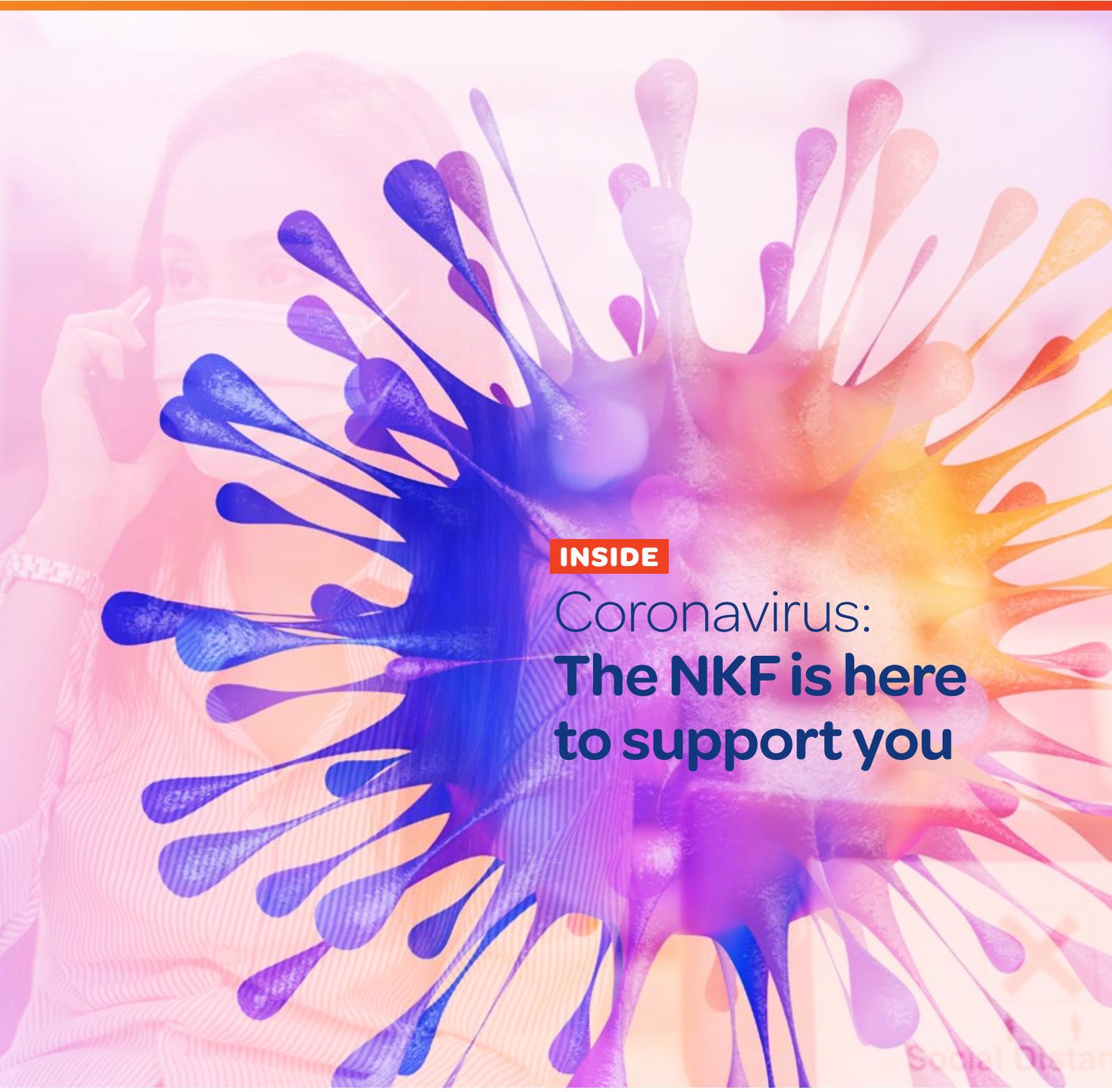


SUMMER 2020 ISSUE

# KIDNEY LIFE

The magazine of the National Kidney Federation



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**The NKF is here  
to support you**



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## Editor's Note...



Welcome to the Summer issue of **Kidney Life**. We are all going through some unprecedented and strange times. It has never been more important for kidney patients and carers to look after both our physical and mental health. That's why in this issue we have brought a variety of personal and heart-warming stories from kidney patients that we hope you will find reassuring and encouraging.

The NKF has always supported patients through tough times, and it endeavours to continue to provide the help to those who need it. See page 12 to meet two of our staff who are available to help you with any kidney related problems you may have in these testing times.

**Look after yourself and your loved ones.**

Sumaya Masood  
Editor

If you have a story for **Kidney Life** please email it to [nkf@kidney.org.uk](mailto:nkf@kidney.org.uk) or give us a call



### NKF OFFICERS

Chairman Jim Higgins, Northants KPA

Vice Chairman Brian Child – North East KPA

Secretary George Palmer – Exeter & District KPA

President Kirit Modi

Patrons Lawrence Keogh and Nina Wadia

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.

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The NKF would like to thank Astellas Pharma for their continued support and for providing a grant for the design and print costs of Kidney Life.



HELPLINE **0800 169 09 36**

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

# NKF supporting patients through the COVID-19 pandemic



A message from the Chief Executive,  
*Andrea Brown*

**It is certainly a very strange and concerning time for us all, the COVID-19 pandemic has had the nation gripped and put into lockdown. We have been sat watching, or reading the daily updates from the start of the pandemic, when there was a few people who contracted the virus to thousands of people contracting the virus and subsequently many thousands sadly dying, a percentage of those people more sadly are our fellow kidney patients.**

The NHS staff and key-workers are certainly to be credited as our heroes during this time, as they go to work to look after us all, putting their own life in danger. To all of these people we whole heartedly thank.

It has been a tough time for kidney patients, getting little help and advice from the government initially. We have and continue to work with our kidney partners to ensure that kidney patients have got and had the best advice and support available and many challenges have been set to try us along the way. Shielding letters took a long time to get out to some patients, some patients wasn't on the shielding list initially. Patients were having to put themselves at risk due to not being able to register as an extremely vulnerable patient for supermarket delivery slots. Many of the problems that have been causing issues had been resolved at the time of writing this.

NKF wrote to Chief Executives of all NHS trusts, to highlight the importance of in centre dialysis patients wearing appropriate face masks before, during and after treatment, we know many trusts are experiencing difficulties in getting the supplies they need to adhere to this, due to the national need of such PPE, but we felt we had to highlight this to protect our extremely vulnerable patients.

We have had many hundreds of patients and carers calling our helpline weekly, for help and advice and I am pleased to say we have been able to help our worried callers with all of the guidance we have in place from our partnership working with others in the renal world.

NKF its self as a charity has come across a few barriers over the last couple of months, we maybe a national charity, but we are only a team of eight staff and five of these staff have had time off ill themselves, which put more pressure on our small team. I am pleased to say that the whole staff team has gone above and beyond to ensure we are supporting all kidney patients and kept 'business as usual', by pulling together and I thank every one of them.

Obtaining funds to keep our charity going to provide support has been another challenge, as public fundraising events have ceased we are relying on donations or grants to help us continue our vital work. If you could make a donation, no matter how small, whatever you can give will make a real difference.

This pandemic will eventually come to an end, but we will always be here to support you.

*I wish you all good health, stay safe.*

Best wishes

*Andrea*

Andrea Brown



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Charity Nos. 1106735 SC049431

Co. No. 5272349 reg. in England & Wales

Give as You Earn contribution No. CAF.GY511



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](mailto: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 Fundraising).

**T: 01263 722287**

**E: [pete@kidney.org.uk](mailto:pete@kidney.org.uk)**

# NKF Helpline during Covid-19

## – Meet the people behind the phones



When it was first announced that public places like pubs and restaurants were closing and the schools and workplaces were also closing due to Covid-19 a great deal of confusion and worry broke out amongst the kidney patients of the UK.

The Helpline telephone lines began ringing constantly with calls about the coronavirus. It was almost impossible for patients to ring their doctors' surgeries and so we rose to the challenge of offering both emotional and practical help.

Whilst the Helpline advisers are not medically qualified to give individual advice, we are very experienced and have dealt with all kinds of kidney related questions. Our vast library of medical information, written specifically for us by medical specialists, is used as our guidelines.

At this point, we had no renal specific information about Covid-19 to help us and we were rather flying blindly but we were able to use our experience to ask the right questions and use our vast library of kidney information to enable us to understand the immediate help that patients needed.

Very quickly the renal specific information for patients was published which made it easier for the Helpline to deal with the many different queries which kidney patients had.

This has been an incredibly busy time for the National Kidney Federation with all staff rolling up their sleeves to offer the best help possible.

Hopefully, this awful situation will soon be over and we can return to our normal lives. The NKF Helpline will be here offering help and advice to kidney patients from all over the UK and we will have seen off this dreadful virus which has been so dangerous to the world.

**Pauline Pinkos** NKF Helpline Adviser



The NKF Helpline has been very busy during the months of March and April due to the coronavirus outbreak. We have received many phone calls and emails from kidney patients and carers looking for information and guidelines to follow to protect themselves from this virus.

All the callers have been really glad to talk to someone and discuss their concerns. Many of the callers have been unable to speak with their GP or consultants, so they have welcomed talking to someone on the helpline. We are experienced in dealing with a whole range of kidney related subjects which is backed by leaflets specially written for the NKF by medical professionals.

As the virus began to spread, further information became available about how Covid-19 affects different kidney patients. Those with Chronic Kidney Disease (CKD), on dialysis, transplanted or with another autoimmune kidney disease. New information was updated frequently for the helpline to follow and we were able to give callers the correct advice.

The main types of calls I have taken are from people with only one kidney, either born with only one kidney or have had one removed. Those who are at stages three, four or five of CKD working in the NHS, shops or busy factories and offices and have been unsure what to do. There have been many calls from those living with kidney patients querying the guidelines to follow so they can protect themselves and the patient. As the weeks have gone by, we have also seen a rise in calls from people on the vulnerable list struggling to get help and support with food deliveries.

On a personal note, I am a kidney transplant recipient since 2011 and I am currently shielding for twelve weeks. These are the guidelines given to me by my GP, renal transplant clinic and the government. I am finding it quite hard to do, but for my own safety, I will continue as it's important to protect myself and my kidney. I do miss going into the office and working with other staff, but the NKF has enabled me to work from home which I am grateful for as it gives me a focus. The helpline is open Monday to Friday from 9am to 5pm. I find it rewarding to help patients during these worrying times. The NKF helpline will continue to help and offer advice to patients through this difficult period and beyond.

**Stephen Emmerson** NKF Helpline Adviser



**HELPLINE**  
**0800 169 09 36**

# A message from Pete Revell

## - Head of Fundraising

**This is a very worrying and strange time for fundraising at the NKF, nearly all of our income streams have dried up with sponsored events either being cancelled or postponed, and the clothes collections across the UK have also been placed on hold due to the pandemic.**

We decided to continue with the April water challenge and some people took part and did fantastic, but lots did withdraw thinking it was a step too far being isolated in their homes and not being allowed to drink tea, coffee or alcohol – and I had to agree. Thank you to everyone that took part, you helped us raise much needed funds.

Thank you to everyone that took part in the spring draw, details of the winners can be found on our web site [www.kidney.org.uk](http://www.kidney.org.uk) and also in the next edition of the In Touch newsletter.

We will get back to normality, and I really hope you can sign up for events and support us once again, but in the meantime you can help us, we have set up various virtual events to take part in.



We have our weekly weather lottery where you could win up to £25,000, plus one to put a smile on your face is the kidney covid cut **#kidneycovidcut**, we want to hear from you, and see the outcome of your home haircuts, good and bad, and maybe the money you have saved on cuts you could donate to the NKF – details of all of these can be found on the **NKF website [www.kidney.org.uk](http://www.kidney.org.uk)**.

**Thank you for your continued support and stay safe!**

## WIN £25,000

With just £1 per week you can help the NKF by taking part in the weather lottery. You can sign up by direct debit, for more information please visit the NKF website at [www.kidney.org.uk/join-our-lottery](http://www.kidney.org.uk/join-our-lottery)



# We need your support even more than ever!

**NKF relies completely on sponsorship and donations to continue its vital work supporting kidney patients and their families.**

The past month has seen income into the charity plummet with events and collections being cancelled and at the same time the services of the charity has seen an unprecedented increase with the helpline being the only dedicated free to call phone line for kidney patients regarding the coronavirus (COVID-19).

**Please help us continue our work and give kidney patients a brighter future**

**Here are the different ways you can help our charity...**

- **Donate** on line at [www.kidney.org.uk](http://www.kidney.org.uk)
- **Donate** using a **credit** or **debit card** by calling **01909 544999**
- **Donate** a regular **gift** by filling in the **form opposite** and **return** to us
- **Send** a **cheque** made payable to the **National Kidney Federation**

**You can also...**

**Leave a Legacy to NKF**

One way of helping NKF is to include a legacy to the charity in your will. More than two thirds of adults die without a valid will, which results in their estates being allocated according to the law, instead of according to their wishes.



[www.kidney.org.uk](http://www.kidney.org.uk)

**HELPLINE 0800 169 09 36**

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



# Introduction from the NEW NKF Chairman

## – Jim Higgins



**I would like to introduce myself to everyone that does not know me, as we begin the new term of office.**

My name is Jim Higgins and I became involved with Chronic Kidney Disease (CKD) in 1999 when my late wife Marion was told she had this problem. Since then I helped her with every form of Dialysis throughout the 15 years she suffered.

After being a transport manager for ten years I had started my own business and was trying hard to expand and grow this, but decided to retire early (aged 57) and concentrate on helping Marion cope with the daily grind of dialysis and all the problems that came with it. Marion was not keen on having a transplant, being scared of any hospital procedure, after convincing her to accept one of mine we found we were incompatible, so that wish never came true and we got on with life as best we could.

Although not a patient, I have been involved for many years, I have continued with Northamptonshire KPA from its foundation in 2003 and served on the committee for the NKF for several years. Marion was also Chair of the NKF from 2010 to 2013.

When first introduced to the NKF I was astonished that a charity could have influence in parliament and with the NHS, and have seen over the years how much this has helped patients. They have raised parliamentary manifesto's, influenced the NHS to keep the tariff for each session of dialysis at the right level and keeping CKD in the specialised healthcare sector.

“

*I know the new Chief Executive; Andrea Brown has the same level of commitment and will continue to uphold these values and I will do my best to help her in that role.*

”

I will look forward to meeting as many of you as possible over the coming months, please stay well and avoid all contact with Coronavirus.

## NKF Annual General Meeting 2020

**The NKF took the decision to cancel the KPA Day, which was due to be held on 4th April 2020, due to the Coronavirus pandemic.**

The AGM was held on that day by teleconference, where 27 people joined a call to do the main business of the AGM, including electing the new officers and members of the NKF Executive Committee, the meeting was chaired by David Marshall, then Chair of the NKF. David Marshall had completed his term as NKF Chair and was being replaced by Jim Higgins.

**The following people were elected:**

**Chairman:** Jim Higgins – Northamptonshire KPA  
**Vice Chairman:** Brian Child – North East KPA  
**Secretary:** George Palmer – Exeter & District KPA

David Coyle, David MacDonald – Wessex KPA, John Roberts – Hope KPA,  
 Michael Sinfield – Six Counties KPA, Glen Smith – Addenbrookes KPA  
 Wajid Iqbal – Manchester Royal Infirmary KPA, John Burdett – Northamptonshire KPA

David Marshall informed the meeting that Ken Tupling was stepping down from his role as President of the NKF and the Executive Committee and had no hesitation in appointing Kirit Modi as the next NKF President.

Ken Tupling said it had been a pleasure and an honour to be NKF's President over the last six years, he thought Kirit Modi was the best person to be NKF President and wished him all the best and knew he would work hard for NKF.

Kirit Modi thanked everyone for their kind words and said he had been humbled and honoured to be approached to be President. He thought Ken Tupling was an excellent President and thanked him for his contribution to the NKF. Kirit looked forward to working with the new Executive Committee.

David Marshall thanked all for attending the teleconference and hoped all would stay safe during the Coronavirus pandemic.

# Tips on Managing Stress and Anxiety



During these uncertain times, the mental health and wellbeing of kidney patients is vital. Here are some tips try out in the comfort of your home.

## TAKE CONTROL

As we continue to spend most of our time at home, it is important to take control of your day by having a routine. Plan your day with activities, movies or even a nice meal to enjoy, so you have something to work toward and look forward to. Not having a routine can eventually become arduous and sometimes lead to stress or anxiety.

## SWITCH OFF AND TREAT YOURSELF

As we continue to stay updated with news and guidelines, it is just as important to sometimes switch off and take time out for your mental wellbeing.

Try pampering yourself at home with a facial, a relaxing bath or treat yourself at the next grocery shop. Watch your favourite movie or TV show or read that book you've always wanted to read.

## EXERCISE AND SLEEP

During the current circumstances we have to ensure that we continue to keep active, even in our homes. Why not try yoga, not only does it help physically, it can aid you to switch off and focus on breathing exercises which can help with anxiety. Or if you prefer something more active, why not try zumba and dance to your favourite tunes. Exercising regularly not only boosts your mood but increases energy levels. However, before taking up any exercise please speak to your healthcare professional.

A good night's sleep is also key for a healthy body and mind. Get into a habit of going to bed on time. If you're having trouble sleeping, try having a warm drink or a relaxing bath or shower before bed. Avoid technology such as watching the TV or using the phone before going to sleep, maybe read a book instead. With warmer weather on its way ensuring the correct temperature is also vital for a good sleep. Some kidney patients often feel very hot during the night, so a cooling pillow has helped some and might just do the trick for you.

## START A HOBBY

This is the ideal time to start on that project you always wanted to do but never had time for. Or just trying something new like knitting, drawing, painting or even cooking or baking? There are many videos and books that will help you get started. For those with gardens why not try your hand at gardening and grow your own fruit and veg.

## STAY CONNECTED

This can be a lonely time for many, so it is imperative to stay connected with loved ones. If you are tech savvy, why not make video calls to friends or family and have a virtual pub quiz, lunch or tea together. For couples isolating together, why not try an indoor date night by cooking a lush meal and getting dressed up.



If you are feeling the pressure of staying indoors and wish to talk to someone then why not ring NKF helpline for free and chat to an experienced advisor, all our calls are confidential – details are on page 3.

The NKF is here for you.

# Faith, Perseverance and Fortitude

By Tauseef Arshad

## A brother's gift of love

**A young, determined and strong-willed transplant recipient, Tauseef Arshad candidly shares the journey of his transplants and gift of life from his brother. Tauseef's bold, brave and courageous attitude sheds light on the emotional impact kidney disease brings.**

### A transplant in my youth

It was in 2003 when my first transplant saved my life at the age of 14, I felt really lucky compared to so many other children at Great Ormond Street Hospital (GOSH), I got a matching kidney after 8 months of being on peritoneal dialysis. I recovered well and the kidney took me through my teenage years and early adulthood. After I turned 18, I had to leave GOSH and all the amazing staff who looked after me and go to another, equally amazing, NHS hospital, Hammersmith Hospital with superb staff.

My kidney slowly started deteriorating in the year 2013, when I was 23. I felt sad and depressed. I could not imagine my life on dialysis again, it was different as a child, I felt protected and cared for but now I was an adult. I spent five long years on haemodialysis at Ealing Hospital with amazing staff who looked after me, but I often got quite sick. My blood pressure and heartbeat would drop and I would pass out, it was very scary. During this time my heart condition was detected as well.

### The emotional impact

I do feel it is important to realise you are scared and depressed because I was. Let it out, cry if you need to, it is OK to shut down, away from everyone at times, if you need to. Talking is vital, share your fears and thoughts, it is important to accept that your feelings are important!

Being young and on dialysis was more frustrating because you have aspirations to do so much but you hardly make it through the days on dialysis. Your body is weak and it feels like you are dragging it every time, your mind and heart want to do something. It's very important to understand that you need to make the most of your days off on dialysis, rest if you need to but plan to do something even if it's a game of cricket in your garden. I used to go out on the weekends even if it was to see my sister at her house.

As kidney patients, it is important to realise that our bodies go through a lot. If you're tired, rest and sleep and don't feel guilty about anything. Do things that make you happy even if it is for a short while. Sleep, eat, rest, pray and watch movies or do anything that makes you happy. You will also realise who are your real friends as it's tough being there for a dialysis patient continuously.

The important thing I realised is not to push away help or the people who care. Accept and appreciate anyone who shows care even if its little things.

The most frustrating and upsetting period of my five years on dialysis was that I had up to fifteen kidney donors matched but when I was called in for a transplant, my blood type would not cross match. The first time it was really heart-breaking, especially for my mum and it got more upsetting every time I was called out, and this was many times.

I am so grateful for my amazing family and my special mentor and counsellor who would talk to me all the way from the USA. Otherwise, the depression I experienced was really lonely and soul-destroying. There were days when I felt everything is in Allah's (God) control and soon I will get a kidney but at other times it felt like nobody understood how hard it is to pretend to act like you are OK when you are hurting inside. Those five years was the most testing time of my life. It was only my faith and my family that got me through these very dark times.

Tauseef enjoying life and new experiences after the transplant operation 



 Tauseef and his brother who donated his kidney

### My brother's gift

Eventually, by the grace of God and by the selfless act by my brother, my life changed as I had a live kidney transplant on 19 December 2018. The immense pressure of having your only brother donate his kidney to you is mixed with feelings of guilt and unworthiness. It was the toughest decision for me to accept his kidney, I even stopped the donation procedure without telling him because I was afraid that the transplant might not be successful and I felt awful thinking that something may happen to him.

In addition to my brother, I have two sisters. One got tested but unfortunately was not a match with me. My other sister is a kidney patient and has had two kidney transplants herself.



“

During this Covid-19 pandemic, I have been blessed with amazing parents who take such good care of me. The last time I left my house was early March. My dad goes out and does all the shopping so I don't have to leave the house.

”

### Taking hold of my future

Following my transplant, I feel I have been blessed with a new life, another chance to live so I plan to make the most of it! I have restarted my work as an extra in Hollywood movies and have had the pleasure of filming with Tom Cruise and George Clooney. I have done things that whilst on dialysis I could only yearn for. I went on a holiday after five years; it was in the UK but I felt so happy to be able to travel. I went to Blackpool and Alton Towers and enjoyed spending time with my family. I am also a huge England cricket team fan so after my transplant, I have also been lucky enough to watch the live cricket match and I went to the Queen's World cup party. I have also been to live shows such as the WWE show and met my favourites too. I feel immensely blessed, but as a renal patient, you can never forget the responsibility of taking care of your kidney. I drink lots of water, keep fit by playing cricket and always take my medication on time as I am also diabetic since the age of 14.

During this Covid-19 pandemic, I have been blessed with amazing parents who take such good care of me. The last time I left my house was early March. My dad goes out and does all the shopping so I don't have to leave the house. The sad part is that I miss my siblings and nephews and nieces who live away, they have not visited my parents or me because of the risk to myself. The good part is we now video call daily.

During this lockdown, it is important for others like me with renal disease, to keep busy with things you enjoy and to relax. I play cricket in my garden and have recently purchased a bowling machine to keep me fit and busy. I have my parents and my sister to keep me company and to my surprise, I have started helping my mum at home a lot more. The current situation with Covid-19 does make me anxious at times, like when will I ever go out and be able to meet my siblings and my friends. Or I worry if I get sick will I be able to fight it and get better. The key is to keep yourself occupied and that is what I try to do. One thing that has always worked for me, is to train your mind to be positive and believe that good things do happen. Even in my darkest times, I have always believed that there is always light at the end.

# Foot Alert

## Looking after your feet during lockdown



**In light of the coronavirus pandemic, Podiatry services are being forced to see only urgent foot problems. Therefore, it is paramount that you look at your feet daily.**

Having kidney issues, you are at greater risk of running into foot complications as a result of swelling in the feet. The circulation to the feet may be compromised or you may have a loss of feeling.

So, if you can check for 5 things in your feet daily which may take only 5 minutes after you shower or take a bath you can avoid running into foot complications.

It is also important that when checking your feet, always compare one foot with the other so you can see at a glance if there are any foot problems.

Here are 5 things to look out for in your feet, highlighted in red = **SCWTTI**:

- S** **Swelling** in one foot or a toe but not in the other foot
- C** **Colour Change** look at signs of redness, blackness
- W** **Weeping** e.g. clear fluid or pus from underneath a toe nail or callous
- T** **Temperature** use the back of the hand to check foot temperature
- T** **Throbbing** pain
- I** **Infection** if you have any of the above you are likely to have a foot infection

The listed symptoms can occur on their own and in renal patients, these symptoms may be dampened as a result of reduced circulation or having loss of feeling. If these symptoms occur in your feet, it's important to contact your local Podiatry department if you are registered with them or your GP.

NEVER neglect these symptoms, they can escalate into severe foot complications in a renal patient very quickly. So, it's important that if you have a foot problem you see the right person at the right time to avoid foot complications and in worse cases amputations.

If you notice a cut or an abrasion (wound) on the foot, then clean it with warm salty water. Avoid cleaning the area with antiseptics, such as Dettol or TCP, since they can be too harsh on the skin and lead to further foot problems.

Once the area is cleaned cover the area with a dry non adherent sterile dressing such as mepore. Avoid plasters since they will macerate the skin and cause a deterioration of the wound. The dressings should be checked every second or third day to see its progress.

### In Lockdown Avoid:

- Walking around the house barefoot; in socks; flip flops or slippers with open back, this can lead to foot problems. For example, the skin will dry on the heels and split (fissure) and cause a foot infection
- If you have been issued insoles/orthotics then these should be transferred into your indoor shoes. These devices will support and control the feet and avoid excessive pronation
- If you have been issued surgical shoes they should be worn indoors as well since they too support and control the feet, much better than your own shoes
- Avoid taking up exercises like running; long walks all of a sudden – since that can lead to plantar fasciitis (pain in the heel and bottom of the foot). When embarking on such activities build them up gradually and wearing appropriate shoes for the activity is paramount. For example, do not go for long walks in slip on shoes, flip flops or mules since these can lead to blisters developing on the feet
- When gardening, always wear closed in shoes to avoid foot injuries
- If you're sunbathing in the garden ensure to use sun cream to avoid the feet getting sun burnt



We would like to hear about your foot concerns or foot problems, so please get in touch with us at the NKF, we are here to help.

We would also be grateful if you are able to complete the Renal Foot survey by visiting the website, [www.surveymonkey.co.uk/r/NYD823N](http://www.surveymonkey.co.uk/r/NYD823N)

This will enable us to capture the gaps in foot care and help raise renal foot awareness.

You can also find information on foot care on the NKF website, in the helpline and information leaflets section on the NKF website at [www.kidney.org.uk](http://www.kidney.org.uk)

Information supplied by Bhajan Jassell, Senior Long-Term Conditions (LTC) Podiatrist.

# Lakeland Dialysis LIMITED

Lakeland Dialysis is truly sorry that many of you have had to have your holidays cancelled due to Covid-19.

Whilst missing you, we have been privileged to be able to help out the NHS in these difficult times by dialysing and caring for local patients.

We look forward to the future when restrictions are lifted. When that happens, whether you are returning or a new visitor we will be able to provide a warm welcome, helping you enjoy your well deserved holiday here in the beautiful Lake District. Let us cater for all your Haemodialysis & Haemodiafiltration needs in a relaxed and professional atmosphere.



**Treatment costs are met by the NHS**

For a booking enquiry or more information please contact

David on **01900 822 888**

e-mail [info@lakelanddialysis.co.uk](mailto:info@lakelanddialysis.co.uk)

or look at our website

[www.lakelanddialysis.co.uk](http://www.lakelanddialysis.co.uk)

**We are situated in the Western Lake District, adjacent to the market town of Cockermouth.**

# Mothers Unconditional Love Gives Son Life Changing Gift

By Shimal Devapura

**Shimal needed a kidney transplant after suffering from kidney failure when he was a baby. Through his mother's unconditional love, Shimal had a second chance at life.**

## Shimal's journey in his words

I had chronic kidney failure for as long as I remembered. It was a normal thing for me to take medications, to drink copious amounts of water and going to the doctors very often. I thought of it as normal and so never compared myself to others. My parents always tried to make me as comfortable as possible, trying to make sure I tried to have a normal life whilst ensuring a healthy lifestyle.

As I got older though, it became obvious that I was different from the other children, but I didn't view it in a negative light. I always tried to focus on the good things in my life such as friends and family, to ensure that I didn't keep myself bogged down from the fact that I suffered from a condition. In 2012 when I was told that a kidney transplant was a very feasible event in my future, as a 13-year-old I was terrified. Honestly, if it wasn't for the amazing doctors at Great Ormond Street Hospital, I would've been much more scared than what I actually felt. I initially thought that having a transplant was deadly, with a high chance of me dying but the doctors ensured both me and my parents, that kidney transplants are quite common and it's not going to be debilitating, in fact, it would be freeing.

As I got older my kidney function deteriorated, I came to accept the fact that I was going to have a transplant and, although my parents worried quite a bit, I was just anxious to try and get it out of the way. Looking back at the transplant now, it seems like a blur. The painkillers I was given made it seem like a dream, I can't remember most of it with only short memories of me being awake. I always had someone in the room, be it friends or family and they really did make me feel a lot better. In my opinion the company helped me to recover faster. I remember when the doctors were encouraging me to try and walk around to improve recovery time, to help me six of my friends walked with me all around the ward!

After the transplant, it felt like a veil had been removed from my eyes. Everything just seemed a lot brighter, food tasted better, I had more energy and everything felt great. The fourteen or so tablets I took every day, have now dwindled to only four.

Now that I'm also a medical student, I appreciate a lot of the procedures that I underwent and whenever I hear one of the medications I used to have, I always smirk to myself because I know what it does!

I must admit, before the transplant, and to a lesser extent now, I had a fear that the kidney would be rejected. It's still in the back of my mind, especially since my transplant was ABOi incompatible but the doctors always reassure me that the kidney is working well and that my kidney function is stable. I knew that the chances of the kidney being rejected were even higher than the usual amount, and I remember being worried about it a lot during the first few months. I had a scare, where my kidney function suddenly dropped but it turned out to be nothing.

I see my scar now, not as a surgical scar, but as the reason behind me being able to live and I can't thank my mum, my family, and the doctors enough.

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After the transplant, it felt like a veil had been removed from my eyes. Everything just seemed a lot brighter, food tasted better, I had more energy and everything felt great.

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◀ Shimal with his mum

## Through a mother's heart

### How it began

Shimal had a very high fever for a long time before he started having fits. The doctors in Sri Lanka were trying for five months, using various treatments for various conditions to try and help but they weren't able to find out what exactly was going on. It turns out he had a blockage of the urethra (which was congenital) and by the time the doctors found out the infections caused by the blockage were too great and had resulted in him getting kidney failure. It was on his first birthday that his first major operation to try and resolve the problem was undergone.

### How I managed whilst he was growing up

I was incredibly sad and worried about my son throughout the duration of him growing up. I always took care of his medications and appointments. It was difficult but I did it. I made sure that the school was accommodating to his problems, especially the fact that during his younger years he needed to urinate very often. From 1999 to 2016 I was incredibly stressed, taking care of him, but the doctors, especially my GP, Dr John and Dr Stephen Mark of Great Ormond Street Hospital (GOSH) and the nurses were incredibly helpful and I am incredibly thankful to them.

### Struggles that were most challenging as a mother

I was always incredibly stressed, more so than normal when he fell ill. Whether it was an infection or a simple cold I was worried that the worst would happen and because of this, I was always worried about taking care of him, making sure he didn't fall ill as much as I could.

### My decision to donate my kidney

Initially, Shimal's father was going to donate but then his kidney function decreased to an amount that wouldn't be suitable for the transplant and as soon as I heard this, I offered my kidney as a replacement. It was needed so I offered it without hesitation.

### The process of donating

Lots of nurses in both Guy's Hospital, especially Anita Coupe, and in GOSH, the transplant nurses, in particular, were incredibly helpful. They were always there to talk to whenever I had questions and they always reassured me that both my son and I would be OK, even though during this time it didn't feel like it. I wasn't worried at all when I went into the theatre because I knew it would be helping Shimal. We received amazing help from the NHS, from transport to medications, the doctors, nurses and all of the staff were always very accommodating to us. I think organ donation is really good. If I could I would give parts of my other organs to those who need it!

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*We received amazing help from the NHS, from transport to medications, the doctors, nurses and all of the staff were always very accommodating to us.*

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### Fear of uncovering other health risks during testing

I was worried that as my husband was tested it was discovered his kidney was not suitable due to his kidney function, that it may also happen to me, but I was determined to try and help my son as much as I could, no matter the consequences it may cause. We also had the opportunity to do a kidney swap but this would have taken far too long and I didn't want my son to be on dialysis, so I took the quicker option and I don't regret it at all.



**A** Brian – living proof that donations save lives

# A Lifetime with Chronic Kidney Disease

By Brian Egerton



**A four times transplant recipient, an organ donation and kidney disease awareness ambassador and an award-winning amateur photographer has not let his lifetime battle with chronic kidney disease stop him from realising his dreams. Brian bravely shares his experiences which we hope will enlighten you during these uncertain times.**

I've been living with chronic kidney disease (CKD) practically my entire life, I was diagnosed with Reflux Nephropathy at the tender age of two and a half months.

When I was born in 1972, I was three months premature. I know I was premature and was on the newly opened Special Care Baby Unit at St. Mary's Hospital in Manchester, but how much premature I have no way of confirming now. As a toddler I can always remember taking trips to Booth Hall Hospital to see the kidney doctor Professor Robert (Bob) Postlethwaite, he was a very stern, old school type of doctor and children were there to be seen and not heard. I always knew from very early on that someday I would end up on dialysis, but even when I was taken on a tour of the dialysis unit at Booth Hall, and was told you have dialysis on those 'big blue machines' it didn't sink in.

In February 1987, dialysis became my reality, but not on one of those 'big blue machines' that I'd been told it would be. No, instead I'm told I will be going on continuous ambulatory peritoneal dialysis (CAPD). I'd never heard of this, not once had it been mentioned so I had absolutely no idea what it was, nor, was I given any choice in the matter. Whether my mother had been asked about it or not I'll never know. Thankfully these days children who are diagnosed with kidney disease are more involved with their treatment, especially in their teenage years.

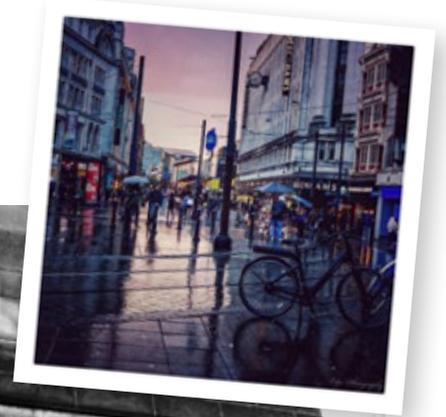
I was only on CAPD for 11 months and on 21st January 1988, I received my first kidney transplant. Unfortunately, that only lasted 10 months but I managed a couple of holidays and competed in the Transplant Games. The other kidney of my donor had gone to a boy at the same time as me. He was 14 at the time and I was 15. Miraculously his kidney has lasted, and now it has been just over 32 years. He only lives 10 miles from me, so the length of transplants can vary for each individual.

So, I ended up back on dialysis and this time it was one of those 'big blue machines,' which didn't seem so big anymore with me now being 16 and not 7 or 8 years old. I'd left school, I was working and basically had a good life besides having to go to the hospital for dialysis 3 days a week. Then, low and behold in October 1989 I was fortunate enough to receive my second transplant. Unfortunately, my second transplant also failed. Subsequently I was fortunate to receive a third transplant; but sadly this was to also fail. I was then given yet another chance and on 20th December 2017 my brother donated one of his kidneys, which became my fourth transplant.

Now, I won't say living with CKD is easy, especially when on dialysis, but you must make what you can out of life. Listen to what your renal team are telling you, they are only doing it for your benefit, not theirs.



Examples of Brian's award winning photography



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You also need something to help you pass the time if you already have a hobby you can carry on doing then great, if not then try something new. It could be anything from cooking or baking, to doing a 5000 piece jigsaw.

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If you are on dialysis or even have a transplant, stick to it, or as near as you can, to the fluid and dietary restrictions they give you, it will make life so much easier. You can live a near-normal life with a transplant and also on dialysis, which may surprise some people. Normally, dialysis at the hospital is three times a week and usually lasts for four hours each time. This is the bare minimum required and longer, slower dialysis is the best as this puts less pressure on your heart. I'm a great advocate for home dialysis, whether that be PD, haemodialysis, and if possible, nocturnal (overnight) dialysis, lasting between 8-9 hours, for 5-6 nights a week. This may sound excessive, but as I said earlier, longer at a slower speed will give you the best possible treatment besides a transplant.

Right now, we are all living in uncertain times with Covid-19 rearing its ugly head. So, like many renal patients, I am also vulnerable. My advice is to stay home as much as feasibly possible if you're on dialysis, and if you have a transplant then just stay home. Make sure you are registered for any help you need and if you live alone you need to have your food and medicines delivered. You also need something to help you pass the time, if you already have a hobby you can carry on doing then great, if not then try something new. It could be anything from cooking or baking, to doing a 5000 piece jigsaw. It's important to share how you feel, especially if you're isolating. If you feel the need to talk to someone there are many groups and patients on social media but if you want to speak to someone confidentially then try out

the free NKF helpline.

I am an avid amateur photographer and I mainly shoot streets and landscapes. I have recently won the 2020 Choice Award on Viewbug (an online photo sharing and competition site) for the red phone box photo. Unfortunately, I have had to put photography on hold because of the current situation. So, I am now trying something new, macro photography which is close up photography. I have shared some of my photography work which I hope will inspire others like me, to focus on hobbies and to remain positive, even during these unprecedented times.

**Remember, your illness doesn't define you!**

**Stay safe, stay well and stay home. We will get through this.**



# Through the Eyes of a Renal Young Adult Nurse

By Rebecca Shelton - Renal Transition and Young Adult Nurse Specialist, St. James's Hospital, Leeds.



*A big part of my role is supporting young people who are on dialysis.*



**While the country grips in the current Covid-19 pandemic and many of us are isolating, the essential work carried out by NHS staff has never been so profound. Rebecca, a renal transition and young adult specialist, is at the forefront and shares her vital role for young kidney patients.**

I am lucky to have the role of renal transition and young adult nurse specialist at St. James's Hospital in Leeds. I have been doing this job now for nearly 3 years. In this time, I have worked with lots of incredible young people who have chronic kidney disease, kidney transplants and those on dialysis. I am based within the adult renal service but work closely with paediatric colleagues here in Leeds to best support young patients who need to transition to adult services.

Healthcare transition has been a long-standing challenge for patients, parents and carers with chronic health conditions. It is recognised that a poor transition or 'a transfer of care' has resulted in poorer outcomes for patients.

My role was created to help improve these outcomes and experience for our young renal patients. We can provide a supported transition by working jointly with the paediatric team based at Leeds General Infirmary. Here the "Ready-Steady-Go transition plan" is initiated and conversations and plans are made towards the transition to St James's Hospital with the adult team. I work

closely with the adult nephrologists who lead on Transition, Dr Andrew Mooney and Dr Madeleine Vernon and at 16 years we meet young people in our transition clinic alongside their paediatric team which we hold in our adult renal outpatient clinic.

We also organise visits to the ward and dialysis areas where appropriate, giving young people and their parents a chance to orientate themselves to the adult team and environment. The adult renal team have been very welcoming of my role and they do a really great job with our younger patients in outpatient's clinic, on the ward or on our many dialysis units.

We have successfully set up a Young Adult Renal clinic where young people can be reviewed alongside their peers. Attendance rates at this clinic have been excellent. Feedback from young people tells us that one to one support from myself in the clinic, on the inpatient ward or on dialysis, is highly valued in helping them settle in the adult service. They have felt more equipped to become more independent and manage their own healthcare as they progress into adulthood.

The nature of the role and supporting young people is broad and varied.

Therefore, I found myself quickly adapting my existing nursing skills to support young people accessing social services, mental health support and local community resources. My role involves coordinating care with renal consultants and other specialities, dialysis teams, ward staff, dieticians, psychologists and primary care providers to ensure the best care for my patients.

A big part of my role is supporting young people who are on dialysis. The commitment of dialysis treatment is difficult and restrictive for all but can be particularly challenging for younger people. Spending time with these young people has helped build their knowledge and understanding of their conditions and treatments, often helping them become more engaged with their care. These young people have to sacrifice so much of their lives to facilitate their dialysis treatments, from missing out on some vital parts of their education to difficult fluid and diet restrictions. Being the youngest person on a dialysis unit can also be a daunting and challenging time.



Rebecca 'climbing out' with friends 



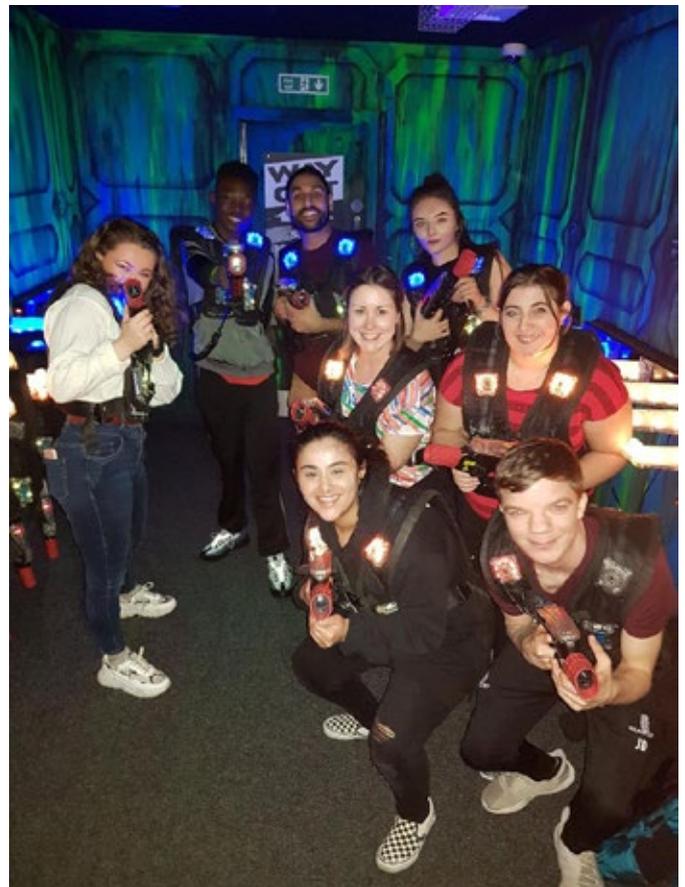
Having fun 

Recognising that young people in our service were spread out, in different dialysis units or transplant clinics, I began to organise some local social activities like bowling and Laser Quest. These were really popular with some of our young people who have begun to build their own social circles and stay in touch and support each other.

The positive outcomes from peer support locally encouraged me to network further with other charities such as Climbing Out, who provide residential breaks for young people with chronic kidney disease. These opportunities have been inspiring and life-changing for some young people and witnessing the friendships and bonds made between them is really moving. I would encourage anybody caring for young people who have a chronic kidney disease to access these residential stays, or indeed those with any healthcare condition can access Climbing Out.

In light of Covid-19, we have all had to adapt the way we work and support our patients, including telephone clinic reviews and supporting clinical areas where needed. We have put a 'pause' on transition during this period to ensure patients are not being moved during these unprecedented times when adult services are particularly stressed. I have been able to keep in touch with lots of young people who are classed as vulnerable and at risk, over the phone and on video calls. I have been blown away by the resilience they have shown at these really difficult times, another example of the strength and determination of renal patients across the country.

**Service feedback and evaluation has shown roles like mine, supporting young people through transition and in adult services is vital to improve outcomes and experience for our patients and ideally should be an essential role in every renal service.**



“

*In light of Covid-19, we have all had to adapt the way we work and support our patients, including telephone clinic reviews and supporting clinical areas where needed.*

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# Hope and Encouragement to Dialysis and Type 2 Diabetic Patients

By Bernard Heys

**Before I begin, I wish to thank all the staff at Airedale and St Luke's Cardiac Team, Airedale Diabetes Team, Bradford BRI, Renal Unit Bradford, St Luke's Renal Team, Skipton Renal Unit and Interserve Home Nurses. Their amazing skill and care have enabled me to complete my autobiography and follow up with this article which I hope will give hope to all suffering from this debilitating illness.**

## The onset of diabetes and kidney disease

In 1998 after a 32-year career managing mega engineering and construction projects around the world, I decided to form my own management consultancy company, advising based on my experience. Two months later I was diagnosed with type 2 diabetes at the age of 48. Starting with diet control and then on to medication, I finally had to move on to slow release insulin control over the next 30 years.

Eventually, at the age of 72 my kidneys started to fail and my diet had to change completely to manage this and I was placed on supplementary medication to slow the onset of kidney failure. At the age of 75 whilst on holiday in Fuengirola, my kidneys failed. I became dehydrated on the flight home, spending the whole flight in the toilet.

Fortunately, soon after returning, I had an appointment with my dialysis consultant. When I entered her office she immediately phoned for the ambulance and arranged for me to be admitted into the hospital where I spent the next ten days in recovery.

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*I was given the choice of dialysis therapy but a kidney transplant was not an option because of other medical conditions I have.*

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## My dialysis therapy and its effects

I was given the choice of dialysis therapy but a kidney transplant was not an option because of other medical conditions I have. Due to my knowledge of poor infection control in hospitals, I initially chose peritoneal dialysis (PD).

I spent the next two years at home on a bedside dialysis machine for nine hours per night, seven nights a week. If the machine failed during the night, I had to phone America for help, usually having to terminate the therapy.

My weight ballooned to 105 Kg due to fluid retention and as a result, I suffered a heart attack. I was in the intensive care unit (ICU) for two weeks and my weight reduced by 25kg through constant dialysis. In retrospect, I concluded that this treatment was not suitable for a person of my age. Not only was the direct treatment a problem but the support infrastructure needed was excessive, including space for consumable storage and stock taking.

Following my period in ICU, I was then fitted with a stent. For twelve months everything went well before I started to feel chest pains again and in November 2018, I was re-admitted with a second, less severe heart attack. On the operating table, I overheard the surgeon, nurses and consultant discussing the situation which turned out to be the collapse of the stent. Their words were very disturbing 'we do not like using these cheap stents.' I commented that I hope they fit a better more reliable version.

We then agreed with the renal consultant that I would switch to haemodialysis (HD) at Skipton renal unit which commenced in March of 2018.



▲ Bernard on his 80th Birthday celebration with his siblings. From left Brian, Peter, Susan, Bernard and David.



◀ Skipton renal unit, a satellite unit of Bradford Hospital

Skipton renal unit is a small ten-bed satellite unit of Bradford Hospital. For the past two years, I have been a haemodialysis patient at the unit. The unit runs a two-shift system starting at 7am and finishes at 5pm.

The staff have to be on-site at 6.30am to organise various machines, allocate therapy stations for patients with varying needs, prepare treatment files and consumables for each patient. By 7am the scene is set to receive patients. The unit runs a taxi service for some patients. Sometimes taxi drivers have acted as porters to ensure that patients are delivered safely to the unit including patients in wheelchairs.

However, positive changes have been introduced slowly and piecemeal awaiting advice from a higher authority. These changes have added to the workload of all the staff involved and some would argue outside their normal job functions. Taxi drivers and family have been restricted from entering the hospital and masks have now been issued to all staff, patients and taxi drivers.

I have three sessions per week, each one lasting four hours. Unfortunately,

my kidneys do not pass any urine at all which means that the entire fluid intake is retained in my body and I have to be very strict as to limit my daily intake.

When I started haemodialysis, I had to have an operation to fit a pair of necklines known as *Hudson Lines* to provide a blood feed and return line to the dialysis machine. These lines have to be flushed and cleaned regularly to prevent infection but in doing this showering becomes the main difficulty. At this point, my PD catheter was still fitted in my abdomen but after one year I had an operation to remove the catheter and form a fistula in my wrist. Once matured the fistula allows the long-term use for haemodialysis and replaces the necklines.

My initial sessions on haemodialysis were not perfect. On several occasions, my blood pressure dropped so quickly that I started to pass out and lose control over my normal functions. The challenge was to find a rate of therapy that I could tolerate without passing out. The solution came in the form of a highly intelligent dialysis machine working

on the principle of 'blood volume monitoring' BVM.

This machine monitors modulates and controls the main bodily parameters that vary through the therapy. The system feeds back signals to reduce fluid take off especially if there is a sudden drop in blood pressure. It can also advise if more fluid could be taken off. If this machine is not available the patient has to signal when they are unwell or is observed by the nurses. I continue to get dialysis there today with great results and a healthy weight maintained at 81 Kg.

### Achievement from my experiences

I believe that there is a purpose in everything. This is evidenced by the fact that I have been able to complete my autobiography, which I started in 2015. I started this in Skipton dialysis unit and I am happy to report that we have now published the book. I am delighted with the quality printing by Book Empire of Leeds. Sales of the book will support 'The Neonatal Tree of Life' a charity directed by my daughter Dr Michelle Heys. Each book sale will contribute £2.00 to the charity.

# A Miraculous Transplant

By David Kemp

## The Beginning

I lived a healthy life until I turned 30 when I suddenly became very ill with a disease that was eventually diagnosed as Wegeners, a form of vasculitis. Wegeners can normally attack various organs but in my case, it attacked my kidneys.

After weeks in Barts Hospital London, I was discharged after having bountiful amounts of cyclophosphamide and steroids along with other concoctions of medicines. A year later I was in remission. I was told that my kidneys were working okay at eGFR 60, but was told that later in life my kidney was predicted to decline quicker than normal and that I would need help.



 On the mend, David in hospital

## Kidney Deterioration

After 28 years and never having Wegener's disease return, my kidneys started to slip away quite quickly. I was placed on the transplant list and was offered dialysis when needed.

My wife Barbara (then aged 54) stepped forward to offer me one of her kidneys. She was the same blood group as me (A+) and amazingly she was a 'match'. However, disappointment soon followed. Tests were carried out to check if her kidney function was adequate enough for her to donate. Although her kidney function was normal, it was on the low side which prevented her from donating.

## A Selfless Offer

Following this setback, one of my good friends and a nurse who I worked with called Pat, stepped forward to see if she could offer me one of her kidneys. This was very selfless of her and an amazing turn of events. Pat was tested to see if she could be a match. Similar to the first time, I was a little nervous about how things will unravel. Following various tests which Pat underwent, it was revealed that her kidney could be used, although it was not a perfect match.

Things started to progress and surgery was planned for April 2019. However, in March my kidney function had drastically fallen to eGFR 5. To my dismay, my kidney function continued to fall by one point each month. During this whole time, I had withheld from starting dialysis, but it couldn't wait any longer as I required dialysis urgently.

I had a fistula made and finally when I went to my first dialysis session my fistula blew whilst needling, so I was unable to undergo dialysis. I was worried and disappointed so I had to rest it before trying again.

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Miraculously, out of the blue, on Thursday 29th March I received a call that a kidney had become available. I was shocked, so I rushed to Addenbrookes hospital not quite knowing what to expect.

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## The Miracle

Miraculously, out of the blue, on Thursday 29th March I received a call that a kidney had become available. I was shocked, so I rushed to Addenbrookes hospital not quite knowing what to expect. When I arrived, I learnt that the kidney from the deceased donor was a better match for me than the one that I was lined up for. So, I decided to go ahead with it. I was nervous and following an eight-hour operation, I came out of the theatre with my new kidney. I soon recovered and was able to return home to my wife and children to start a new life, free from dialysis.

I am forever grateful to my deceased donor and their family. Without them, I wouldn't have received this beautiful gift. Although the live kidney transplant from my friend Pat and my wife did not go ahead, I am thankful for their act of generosity.

# Alport syndrome

## What is Alport syndrome?

- Alport syndrome is an inherited kidney disease
- It runs in families and is caused by a genetic mutation
- Men are more severely affected than women
- It can lead to deafness as well as kidney failure

## Why it is called Alport syndrome?

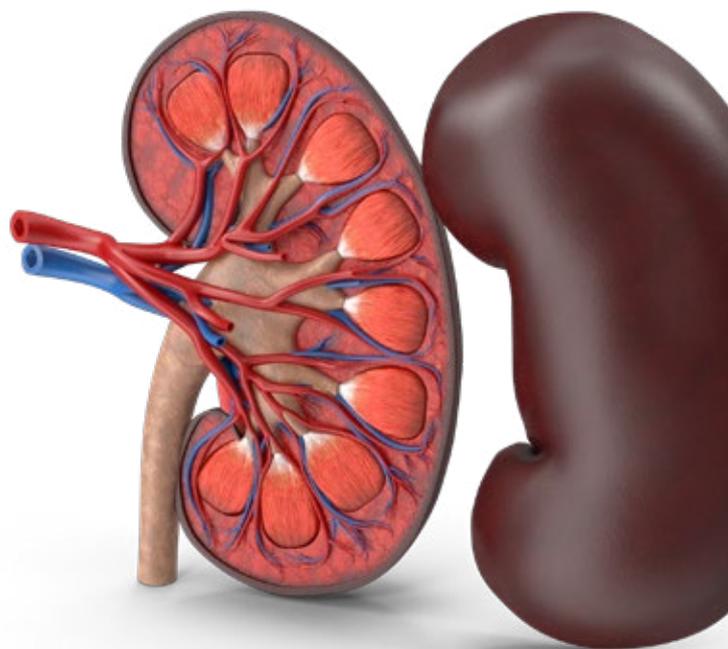
- Alport syndrome is named after Dr. A. Cecil Alport, who graduated as a doctor in Edinburgh and first recognised families with the syndrome in 1927

## Causes of Alport syndrome?

- Caused by an abnormality in collagen in the body
- Collagen is a 'building block', giving parts of the body that is not sustained by bone their shape and strength
- There are several types of collagen but type 4 collagen is important for the kidney, ears and, to a lesser extent, the eyes
- Type 4 collagen is the collagen that is abnormal in Alport syndrome
- The abnormality occurs because the genetic code, which tells the body how to make collagen, is abnormal

## How is Alport syndrome diagnosed?

- If Alport syndrome is known to run in the family, a simple test for blood in the urine may show a diagnosis
- Someone with kidney disease might have a kidney biopsy (sample of a kidney removed with a needle) – Alport syndrome can be diagnosed because of its unique appearance
- Testing for the abnormal gene in Alport syndrome is sometimes possible



## Treatment to prevent kidney failure in Alport syndrome

- There is currently no cure for Alport syndrome, the abnormal gene cannot be replaced with a normal one
- Rate of kidney damage may be reduced by careful treatment methods
- High blood pressure is the most important factor that can speed up the decline in kidney function
- The strict control of the blood pressure can break this cycle, delaying the need for dialysis by years in some cases. There is some evidence that high blood pressure can start in childhood so that starting treatment for high blood pressure even before the age of 10 can be beneficial

## Does everyone with Alport syndrome develop kidney failure?

- Most men go on to develop kidney failure between 15-30 years, but in some families, this can be delayed until 50-70 years
- Around 1 in 10 women with Alport syndrome develop kidney failure
- A rare type of Alport syndrome can cause kidney failure in childhood

## Can people with Alport syndrome have dialysis or a kidney transplant?

- Alport syndrome does not cause particular problems with dialysis
- Kidney transplantation can be performed in someone with Alport syndrome, just as it can with many other kidney diseases

This information was taken from the NKF leaflet, **ALPORT'S SYNDROME**. Information is specially written for the NKF by medical experts. If you would like to read about the inheritance of Alport syndrome and the need for testing family members, you can request a copy by calling our free helpline, see page 3 for details.





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