



Supporting and working for  
kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association

# Newsletter

Spring 2023



*Photo by Daniel Loftus on Unsplash*

**W**elcome to the Spring 2023 Newsletter.

We start this year, as with every year, filled with vigour and optimism for the coming twelve months. Spring is in the air and the natural world is coming out of hibernation. For some, new year's resolutions are a distant memory while others are already dreaming of their summer holidays.

The WLKPA would really like to hear from you – our dearest members – if you have any ideas for events or fund raising activities we could embark upon over the coming months. You can get involved in so many ways from brainstorming, planning or delivery of such events. We welcome feedback from everyone...

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## The Tribulations of Returning To Work

by Chetan Joshi

**I began haemodialysis in April 2013. I think it's fair to say that my personal life up until then, had been quite turbulent. I had had an almighty stroke ten years earlier in 2003 which I put down to stress.**



At the time, I felt like I was humbly piecing my life back together from scratch after this near fatal attack. On top of learning how to walk and talk again, I had to once again begin the climb up the career ladder from the bottom rung after having already reached senior positions with former employers.

So, when I got a line infection in May 2013 just weeks after starting dialysis, I found myself in hospital with my life once again teetering on the edge. After some time however, I was able to return home. On the journey home, my sister who also happened to be my work colleague, informed me that the boss had decided to make me redundant as work had become thin-on-the-ground.

And thus began a period of unemployment that has loomed over my head like a dark cloud ever since. Having a pragmatic sensibility though, I took it on the chin and accepted my fate.

After the stroke I had years earlier, I was forced to make the unenviable decision to move out of my house and back into the family home with my parents, sisters and elderly grandmother.

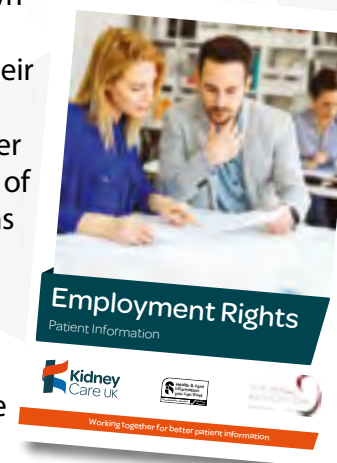
After just over two years on dialysis, I was blessed with receiving a kidney transplant in August 2015. I was filled with renewed hope and optimism that life will soon return to normal. Throughout the time I was on dialysis, I had applied for many jobs, but in vain. I recommenced my job search after the transplant which was also yielding no fruit.

So it came as a pleasant surprise to me when I was recently shortlisted for an interview for what felt like the thousandth job I had applied for. Unusually, the interview was to be conducted over the phone.

On the day of the interview, I was filled with nervousness and anticipation of the impending phone call I was to receive. I knew that I was more than qualified and experienced for the position I was applying for. I felt so ready.

The phone rang at the allocated time. I answered confidently as we began to engage with the usual pleasantries. Then came the question, "So why do you want to work for us?"

Two seconds or an eternity of silence passed by and I became numb. A flood of memories filled my mind of all the trauma and grief I had been through. Haunting faces and voices of people I had known who were no longer around, attending their funerals, the mental anguish I had felt after undergoing all kinds of medical interventions over the years, the claustrophobia of having to live back at home because I couldn't afford to live in my own house, the covid pandemic, the war in Ukraine, the Cost of Living crisis, the general bleakness of life. The compounded effect of all these experiences flashed through my mind in an instant.



I took a deep breath and gulped. I think I managed to string together some words in a feeble attempt to provide an answer to the question that was put before me. I fumbled through the rest of the interview and was filled with bitter-sweet emotions when it finally ended. I was filled with regret at my performance and the quality of the answers I had given.

Inspite of my apparent lacklustre performance on the phone, they seemed impressed with me enough to invite me for a face-to-face interview a week later. I remain ever hopeful that something positive will transpire from this.

KidneyCare UK have produced a leaflet on Employment Rights which can be read and downloaded from their website

[www.kidneycareuk.org/media/documents/Employment\\_rights.pdf](http://www.kidneycareuk.org/media/documents/Employment_rights.pdf)

If you wish to share your experiences of returning to work after a transplant whether good, bad or

ugly, we would love to hear from you and perhaps you might inspire others if we include your story in future issues.



## Ealing dialysis unit refurbishments

by Helen Watts

One of the challenges that we face as a service is keeping the estate and equipment up to date. Financial restraints and the logistics of upgrading dialysis units when patients rely on the service can be difficult. The Ealing unit recently had to meet such a challenge in more ways than one. Firstly there was water supply failure due to works in the local area, which meant that patients could not be dialysed at their regular time. The nursing staff led by Colin Smith quickly responded, calling the technical team to identify the problem and reorganised the patient sessions, dialysing well into the night. They had the support of the Community ambulance service to reorganise patient journeys. All patients were kept safe and cared for.



Following this the team again had to reorganise the service to close the unit for a full weekend to have upgrade to the water treatment room installing a new platform. This involved careful planning and relocation of patients to the Hayes unit on a Sunday. The technical, transport & nursing team at Ealing & Hayes worked together to ensure good communication and support to the patients. All went well and the unit reopened successfully on the Monday morning. Colin had secretly organised for

the unit to be repainted during the closure which was a lovely surprise for the staff and patients when they returned. In recognition of their excellent work the team have been awarded an instant recognition Make A Difference award for their team collaboration and good spirit. We would also like to thank the patients at Ealing for being so accommodating and flexible during what must have been a difficult time for them.

# KIDNEY HEALTH FOR ALL

PREPARING FOR THE UNEXPECTED,  
SUPPORTING THE VULNERABLE!



#worldkidneyday #kidneyhealthforall  
[www.worldkidneyday.org](http://www.worldkidneyday.org)

World Kidney Day is a joint  ISN  IFKF-WKA initiative



## How Adult Polycystic Kidney Disease is Treated

by Professor Vassilios Papalois

**Autosomal dominant polycystic kidney disease (ADPKD) is the consequence of a genetic mutation that results in disorganised cell growth and fluid secretion and accumulation in the kidneys that finally result in the formation of massive cysts that completely replace the healthy kidney tissue. The kidneys become massive (sometimes up to 50 cms in length) and their weight can be sometimes more than 5 Kg each (Figure 1).**

ADPKD is the most common inherited kidney disease and is the fourth most common cause of kidney failure worldwide. It is therefore a challenge that we treat very frequently in a large renal and transplant programme like the one of the Imperial College Healthcare NHS Trust.

Clinical problems in ADPKD patients include:

- Haematuria (blood in the urine)
- Bleeding or infection in the massive cysts
- Urinary tract infection
- Loin or abdominal pain
- Abdominal fullness, discomfort and difficulty to eat
- Kidney stones
- High blood pressure

The patients who have APKD may also frequently have:

- Polycystic liver disease (liver tissue replaced by giant cysts)
- Problems with the valves of their heart
- Aneurysm (vessels which are distended dangerously) in their brain
- Aneurysm of the abdominal aorta (main blood pipe that supplies blood to every organ in the abdomen)
- Diverticular disease (weak areas on the bowel wall)
- Bronchiectasis (distention of the windpipes of the lungs)

The polycystic kidneys are removed surgically (bilateral nephrectomy) for three main reasons:

- Severe and persistent symptoms: frequent infections, bleeding, fullness, difficulty to eat, breath or move, chronic pain
- Suspicion of tumour in the kidneys
- Create space for a kidney transplant

Literature reports that approximately 20-30% of the patients with APKD will require surgical intervention. At the Hammersmith, we have one of the biggest and most successful programmes of removal of APKD in the UK. This major operation allows our patients to:

- Have a much better quality of life without debilitating symptoms and the suspicion of tumour in their kidneys (40% of our patients).
- Have space in their abdomen for a successful kidney transplant (60% of our patients).

As always, the success of this major operation depends totally on close collaboration, meticulous preparation, and tight post-operative monitoring by a dedicated and experienced multi-disciplinary team.

This is one more example of top quality care offered to our patients. If you have APKD and you need more information and a more in depth discussion, we would be delighted to see you in the surgical or transplant clinics at the Hammersmith or our Satellite Units.

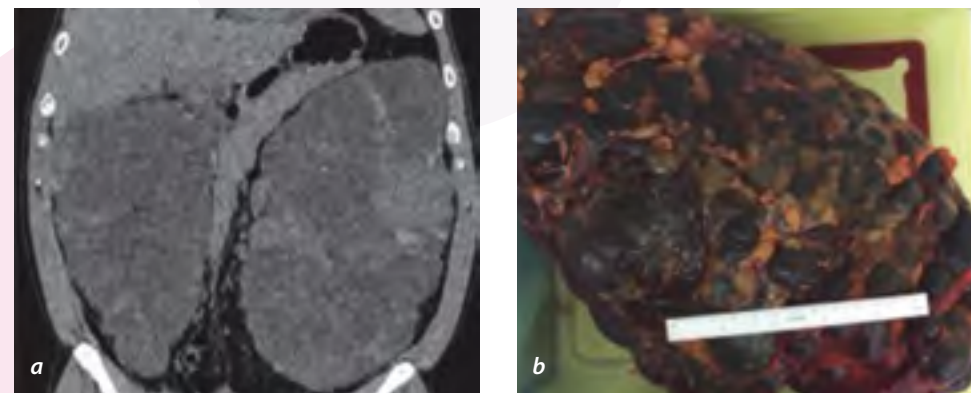


Figure 1. (a): massive polycystic kidneys on CT scan (more than 5 times the size of normal kidneys). (b): a polycystic kidney following surgical removal.



## Changes at West Middlesex University Hospital

by Shameema Ali

The journey towards building a new diagnostics and treatment centre at West Middlesex University Hospital has reached an important stage, with planning permission now granted by the local council. Once formally agreed, the Ambulatory Diagnostics Centre (ADC) is expected to offer treatment and support for people living with kidney disease in Hounslow, Richmond and Ealing.



Artist impression

Cancer and renal disease account for one of the largest health impacts for the local population. The ADC will double capacity for these services, ensuring that the local community can access treatment locally whilst significantly reducing patient travel times as they no longer have to attend other hospitals further away.

The design of the new build will be considerably more 'green' resulting in a noteworthy reduction of its carbon footprint. The new build will have a central piped dialysate system. The piped solution means the trust will not require plastic containers resulting in a huge reduction in plastic waste.

Fergus Hampton, dialysis patient, said:

*"As a dialysis patient at West Middlesex Hospital, I fully support the plans for a new centre to provide for the growing number of local people who need this service."*

The centre will support outpatient care and will offer day services for patients, opening approximately 12 hours per day, 6 days a week.

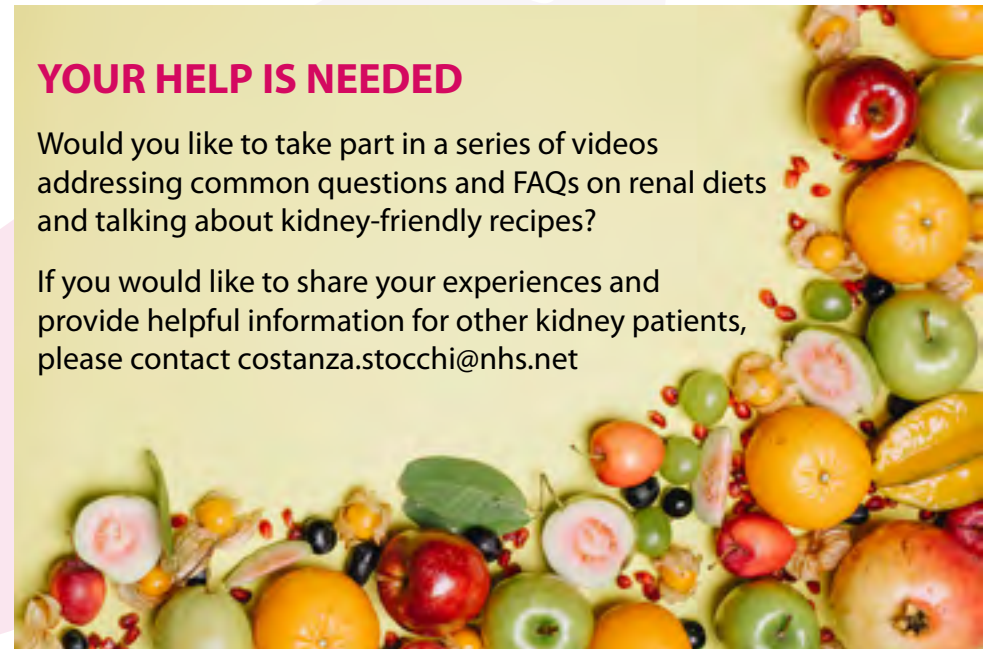
Final approval for the plans is due in September 2023, and it is hoped that the ADC will open in January 2026. We'll share further updates in due course.



### YOUR HELP IS NEEDED

Would you like to take part in a series of videos addressing common questions and FAQs on renal diets and talking about kidney-friendly recipes?

If you would like to share your experiences and provide helpful information for other kidney patients, please contact [costanza.stocchi@nhs.net](mailto:costanza.stocchi@nhs.net)







## Spring into Easter Stress-free

by Katie Brooker (Dietitian)

### Do your eating habits change when you are under stress?

**Everyone goes through periods of stress; when it comes to eating, the impact that stress has on our daily food habits changes from person to person. Some people may find that stress reduces their appetite, whereas others may end up eating bigger meals, unhealthier foods or grazing when they don't feel hungry. This is often referred to as comfort or emotional eating.**

These eating patterns can lead to unwanted weight changes. Maintaining a healthy weight is important, particularly in renal disease, so in this issue we will be focusing on how to address emotional eating and prevent stress from impacting our eating habits.



#### Emotional eating

Do you find yourself reaching in the snack cupboard or contacting your local takeaway when life becomes stressful? Well, you are not alone. In 2020, a survey from

the British Nutrition Foundation found that 45 percent of people named 'stress, anxiety and tiredness' as their main reasons for eating less healthily or eating more during the COVID-19 lockdown.

#### So how can you change these habits and be healthier this Spring?

Mindful eating is a helpful way to prevent overeating. It involves focusing solely on the meal we are eating and avoiding any distractions. Eat your meals at a table, if you can, and avoid having the TV on or being on your phone during meal times. These devices can distract you from how much you are eating and disrupt the signals which tell our brain we are full. If we do not engage in mindful eating it can become easy to eat more than our body needs, which can lead to unwanted weight gain.

As well as eating mindfully, try having regular, balanced meals to prevent the temptation to grab snacks that are higher in fat, sugar or salt. Small, frequent meals can help, keep you energised, boost your metabolism, prevent extreme hunger and can be a good way to ensure portion control to prevent emotional eating.

### Easy stress relievers to take up this spring

We all face stresses from time to time, however sometimes, a leisure activity is all we need to shift our focus away from stress, keep us active and prevent emotional eating. Instead of reaching for the snack cupboard, try some of the suggestions below:

- Yoga - find free videos online or join a local class with a friend
- Meditation - you can find free apps or videos online to help de-stress – Headspace is a good place to start!
- Reading - find time to escape into your favourite book or newspaper
- Spend time outdoors - Going for a walk either by yourself with your favourite music/podcast, or with a friend. Spend more time in your garden or local park.
- Start a form of exercise which you ENJOY! Exercise has been found to be an effective stress reliever - try to find one you enjoy and are more likely to stick to!
- Take up a hobby or develop new interests
- Get into a new TV series - ask friends/colleagues for recommendations
- Cook a new recipe for family and friends - free recipes can be found online on [kidneycareuk.org](https://www.kidneycareuk.org)



This is your reminder to focus on your wellbeing and take time to do things you enjoy this Spring. If you are finding your stress levels debilitating or higher than usual, speak to your GP and check out the Mind UK website - [www.mind.org.uk/information-support/helplines/](https://www.mind.org.uk/information-support/helplines/)



West London KPA will have a World Kidney Day awareness table on Thursday 9th March in the main foyer at Hammersmith Hospital.

We'd love to see you. Come and say Hi and have a chat with one of our friendly volunteers.



### KIDNEY HEALTH FOR ALL

Preparing for the unexpected.  
Supporting the vulnerable.



**The Westfield Health British Transplant Games are set to go ahead this summer in Coventry from 27th-30th July.**

Registration is open to all transplant patients – live donors and receivers, regardless of ability. The event is a wonderful opportunity to meet with fellow patients from across the country. There will be social events as well as sporting events to mingle with each other and make new friends.

If interested, contact the Team Manager –  
**Dino Maroudias**  
07708808808

## A BIG THANK YOU



The WLKPA would like to say a **BIG Thank You** to everyone who has supported us over the past year. Whether you bought Christmas cards, walked, climbed, jumped, swam, baked, sang or danced to raise funds or simply donated whatever you could afford, it all makes a difference.

## Christmas Festivities at Northwick Park



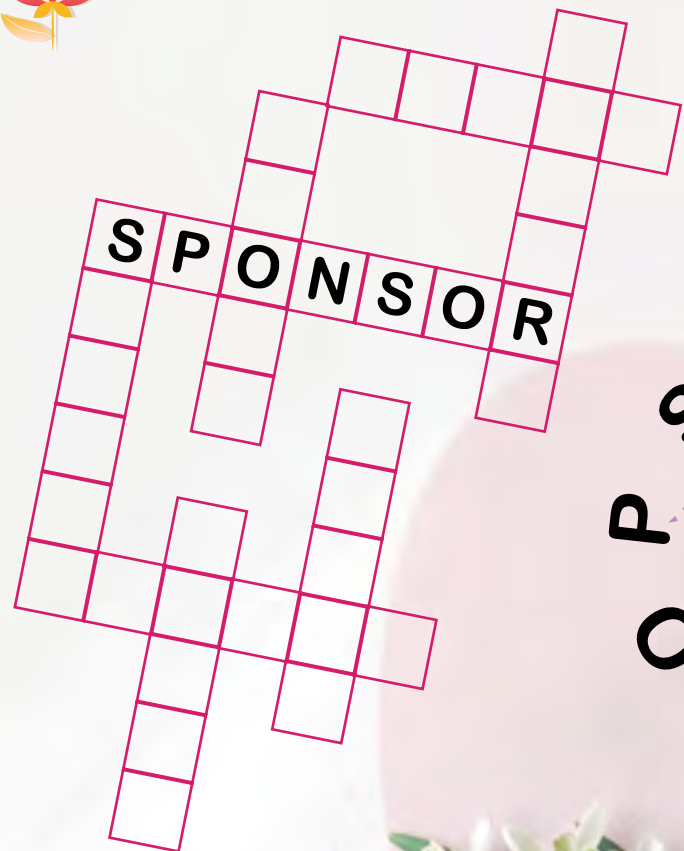
Christmas may be a distant memory for most of us but these snaps sent in from Northwick Park dialysis unit will ensure the warmth of the holiday season remains with us throughout the year.



## NEWS ALERT

The Falck transport system has new ownership being bought by 'Community Ambulance Service'. There have been difficulties with the previous service and the new owner Joe Sheehan is working hard in collaboration with the Trust transport team and renal lead nurses to make revisions to improve the service for our patients.





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**Snowdrops  
Criss-Cross Puzzle**

Can you find eight words  
to fill the criss-cross puzzle  
using the letters in the word  
SNOWDROPS?

We've given you one  
word to get you started

Answer is on the website.



**Springtime Butterfly Pairs Puzzle**

One of these butterflies doesn't have a  
matching buddy. Can you spot which one?



**COFFEE  
BREAK  
PUZZLE**



# Imperial College Renal & Transplant Centre

## Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	020 3313 6627
Brent Renal Unit, Central Middlesex Hospital, Renal Unit	020 8453 2017
Charing Cross Hospital , Renal Dialysis Unit, 1 South	020 3311 1752 / 020 3311 1034
Ealing Hospital, Renal Unit	020 8967 5737
Hammersmith Hospital , Renal Home Therapies (HD)	020 3313 6649
Hammersmith Hospital , Renal Home Therapies (PD)	020 3313 6647 / 020 3313 6665
Hammersmith Hospital , Renal Out-Patients' Clinic – Currently joined with St Mary's Hospital, Renal Unit	020 8383 8333
Hayes Renal Unit	020 37048 450 / 020 3704 8444
Northwick Park Hospital, Renal Unit	020 8869 3245
Pam Sasso Unit (PIU), Hammersmith Hospital	020 3313 6682
Renal Dietitian, Nutrition & Dietetics	020 3311 1034
St Mary's Hospital, Renal Unit – Currently closed. Joined with Hammersmith Hospital, Renal Out-Patients' Clinic	020 8383 8333
St Charles Dialysis Unit, E & F Block	020 8962 5197/5196
St Charles Dialysis Unit, G & H Block	020 8962 4816/4815
Watford General Hospital	01923 217243
West Middlesex Hospital	020 8321 2543

**Contact us: [info@westlondonkpa.org](mailto:info@westlondonkpa.org)**

**Or visit [www.westlondonkpa.org](http://www.westlondonkpa.org)**

The West London Kidney Patients' Association (WLKPA) Newsletter is published four times a year.\*

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