



Supporting and working for
kidney patients in West London

Registered Charity 275771

The West London Kidney Patients' Association

Newsletter

Autumn 2023



We shall all be witnessing scenes like this image in the coming months. Well, not this exact scene as this image was created using Artificial Intelligence (AI). AI is revolutionising our world. Read more about it inside.

WLKPA will be celebrating the Gift of Life during Organ Donation Week from Monday 18th September to Sunday 24th September. More details on page 12.

Contents

Page 2-3

The Advantages of Artificial Intelligence in Kidney Care

Page 3

British Transplant Games Coventry 2023 Roundup

Page 4-6

Reclaiming the Ultra Low Emission Zone (ULEZ) charge

Page 7

Enjoying the outdoors on a budget

Page 8-9

Renal Counselling & Social Support Team

Page 10-11

Looking after your gut health with CKD

Page 12

Organ Donation Week (ODW) 2023

Page 13

Sue Sandeman's decision to donate a kidney to her good friend Sarah

Page 14

WLKPA AGM Notification & Agenda

Page 15

Reminder and Puzzle

Page 16

Useful Numbers

Winter issue - December 2023

Editorial deadline: 10th Nov

To submit an article for consideration

email: editor@westlondonkpa.org

Empowering Kidney Patients: The Advantages of Artificial Intelligence in Kidney Care

by Chetan Joshi (assisted with AI)

You may have noticed the proliferation of AI in society lately. This emerging technology is set to play an increasingly significant part in our lives as medical and pharmaceutical industries are tapping in to the possible uses of AI. This article is a summary of the response generated by AI after I posed the question, "What are the benefits of AI to kidney patients?" It's an interesting read...

Artificial Intelligence (AI) has revolutionised the healthcare landscape, and kidney patients are among the beneficiaries of this cutting-edge technology.



Early Detection and Diagnosis:

One of the crucial benefits of AI in kidney care is its ability to facilitate early detection and accurate diagnosis of kidney diseases. AI algorithms analyze vast amounts of patient data, including medical history, lab results, and imaging studies. By identifying subtle patterns and risk factors, AI can flag potential kidney issues at an early stage.

Personalized Treatment Plans:

Kidney diseases can vary greatly from one patient to another, and treatment responses may differ significantly.

Drug Development

AI has accelerated drug discovery and development, leading to the emergence of precision medicine in kidney care.

Remote Monitoring and Telemedicine:

AI-powered remote monitoring systems, coupled with wearable devices and sensors, enable real-time data collection.

Predictive Analytics and Risk Assessment:

By analyzing historical patient data and relevant medical literature, AI algorithms can predict disease progression and potential complications.

Enhanced Patient Engagement and Education:

AI-powered educational tools and platforms provide kidney patients with essential information about their condition, treatment options, and self-management strategies. These resources empower patients to actively participate in their care, make informed decisions and adopt healthier lifestyle choices. By fostering patient education and engagement, AI strengthens the patient-provider relationship, leading to better treatment adherence and improved overall health outcomes.

British Transplant Games Coventry 2023 Roundup

The Westfield Health British Transplant Games took place this summer in Coventry. Although we had a modest sized team, we made up for it in enthusiasm and we triumphed with seven medals across ten events.



Gold in long jump, 100m, 200m, squash. Silver in 10 pin bowling and table tennis and bronze in 5km road race.

Well done to Robert in the 200m and 1500m who came a very close 4th in these categories with some tough competitors!

If you're interested in joining the team next year in Nottingham, remember that registration begins early 2024. Please get in touch.

Reclaiming the Ultra Low Emission Zone (ULEZ) charge Information for patients, relatives and carers

The following article is taken from the official Imperial Trust website. It can also be downloaded from our website [here](#). The download file also contains a form to claim the reimbursement.



To help improve air quality, an Ultra Low Emission Zone (ULEZ) operates 24 hours a day, 7 days a week. ULEZ has now expanded from central London up to (but not including) the North Circular and South Circular roads.

All five of our hospitals are within the ULEZ which means that if you choose to drive to your appointment, or are driven by a family member or friend, your car will need to meet the ULEZ emissions standards or you will have to pay a £12.50 daily charge. To find out if you meet the standards please

visit: <https://tfl.gov.uk/modes/driving/ultra-low-emission-zone>

How do I pay the ULEZ charge?

You can call Transport for London (TfL) on 0343 222 2222 or pay online: <https://tfl.gov.uk/modes/driving/pay-to-drive-in-london>

Reimbursement for NHS patients

If you meet specific health-related criteria, you can reclaim the daily charge via the hospital. You will need to pay the charge first and then claim it back at the hospital. The hospital then claims the money back from TfL.

What are the reimbursement criteria?

You are eligible to claim if you are clinically assessed as having an illness, frailty or disability that prevents you from using public transport and you:

- have a compromised immune system
- require regular therapy or assessments
- need regular surgical intervention

You must be attending hospital for a consultation, diagnostic test or to have treatment to be eligible for reimbursement.

NHS patients who are clinically assessed as being at moderate or high risk of coronavirus are also eligible currently.

Who checks that I match the criteria?

Your hospital clinician will use the clinical criteria to check if you are able to reclaim the charge.

How to reclaim the ULEZ charge

1. First you will need to pay the charge. TfL recommend paying on the day you travel, not before, in case your appointment is

cancelled.

2. Keep your ULEZ charge receipt as you will need to give this to the hospital cashier.
3. Ask for a 'ULEZ charge patient claim form' when you arrive in the department for your appointment.
4. You need to complete sections A and C. Ask the hospital clinician to complete and sign section B.
5. Take the signed form and your ULEZ charge receipt to the cashier's office at one of the following hospital sites:
 - St Marys Hospital, ground floor, Queen Elizabeth Queen Mother (QEQM) building
 - Charing Cross Hospital, ground floor
 - Hammersmith Hospital, ground floor, north admin block. Our cashier's offices are open from 10.00 – 13.00 and 14.00 – 16.30, Monday to Friday.

Please note:

- In Section B of the claim form ('Category of claim') your hospital clinician must sign both box one and box two for you to receive your payment.
- You will need to pay the ULEZ charge first, so you do not incur a penalty charge (PCN). Please note that there is no reimbursement for penalty charges.

(continued on next page)

Can I claim for more than one appointment visit at a time?

Yes, you can claim for multiple visits on one claim form. Complete the details, as before, for up to five appointment visits on the same patient claim form.

In Section A 'patient details', list all the appointment dates. You must be able to provide the charge receipt and vehicle registration number for every appointment listed.

Can I reclaim the charge after I attend my appointment?

You can claim back the charge for up to three months after the date

of your appointment. You will need a completed patient claim form to support your claim.

If I travelled to my appointment as a passenger in a vehicle, can I still make a claim?

Yes, as long as you match the criteria for reimbursement. The scheme applies to the vehicle used by an eligible patient. Complete the claim form as usual, with the details of the vehicle you travelled in and keep your charge receipt. Only one person per vehicle can apply for reimbursement.



Map of London showing the coverage of the Ultra Low Emission Zone in green

Enjoying the outdoors on a budget

by Michelle Delon

As I was writing this, I was really thinking about what is different for us, living in London as opposed to people living around the country. We don't have easy access to beaches or rolling hills, the cost of living crisis hits Londoners really hard and this, combined with being unwell or having a chronic health condition can mean that it becomes challenging to see what London can offer.

So in this very short piece I have listed some places that are free (or cheap) that can be accessed for adults and children.

London Zoo:

London Zoo has a discounted ticketing service for people receiving means tested benefits (such as universal credit). Tickets are reduced to £3/person. Tickets must be booked online and on their website.

Natural history Museum & Science Museum:

Most of the big London museums are free to enter and often have free activity packs for children. Some offer free carer tickets for the paid exhibitions. The National History museum has a small number of parking spaces for Blue badge holders that can be booked online and wheelchairs can be hired for free.

Eating Out:

During the school holidays, many restaurants provide cheap meals or free meals for children. For example, Tesco offer a free kids meal with any adult purchase of more than 60p when showing their tesco clubcard at the till.

Too Good To Go:

This app offers you a "magic bag" of rescued food at your local shops and restaurants. For around £2.50-£5.00, you can rescue a bag of food worth at least double or triple the amount. The app can be downloaded from your app store and includes smaller restaurants as well shops such as Greggs, Morrison's and Aldi.

Renal Counselling & Social Support Team

The Renal Counselling & Social Support Team at Imperial College Healthcare Trust are continuing to offer counselling and social support. We are able to see patients for face to face booked appointments in the hospital setting and also offer telephone counselling and social support.

We look forward to offering our continued support and assistance to all our patients.

We are aware that sleep problems / insomnia can be an issue for many of our patients.

Sometimes the changing seasons may increase this problem.

The link below provides good tips and advice for getting a better night's sleep

<https://www.nhs.uk/every-mind-matters/mental-wellbeing-tips/how-to-fall-asleep-faster-and-sleep-better/>

Have a good sleep routine:

Having a regular routine helps to improve sleep. It's sometimes called sleep hygiene.

A good sleep routine should include having a set time to start winding down – and a way to relax is important too.

Going to bed and getting up at fixed times is another good sleep habit.

Ideally, a sleep routine should be the same time every day, including weekends.

Relax, unwind and try sleep meditation:

Remember, your sleep routine starts before you get into bed, so build in time every evening to relax.

Avoid electronic devices at least an hour before bed, as mobiles, tablets and computers all throw out blue light that stops sleep.

Reading, listening to music or a podcast, or sleep meditation can all help if you have trouble sleeping.

Try some guided mediation for sleep, like NHS Beditation relaxation video

Try mindfulness for sleep:

Anxiety, worry and stress can affect how well we sleep. Luckily there are things you can do daily to help manage your worries, like talking to someone you trust or writing in a notebook about your concerns.

If you often lie awake worrying, set

aside time before bed to write a to do list for the next day – this can be a good way to put your mind at rest.

Create a good sleep environment

It is generally easier to drop off to sleep when it's quiet, dark and cool – although the right environment is personal, so try different things and see what works for you.

Silence is golden when it comes to sleep for many of us, so wearing earplugs, putting your phone on silent (or out of the room entirely) can keep things quiet.

Good curtains or blinds can help to keep a room dark and avoid unwanted lights by keeping clocks out of view and phones facing down.

Make sure your room is the right temperature for you and well ventilated, as a cool room is usually better to sleep in than a hot stuffy one.

Some people also find it helps to play music for sleep, such as ambient sounds like rainfall, gentle music or white noise.

Do not force sleep:

If you're lying awake unable to sleep, do not try to force it. If you're tired and enjoying the feeling of resting, then sleep may naturally take over.

But if you cannot sleep, get up and sit in a comfy place and do something relaxing, like reading a book or listening to quiet music. Only go back to bed when you feel sleepier.

Improve sleep through diet and exercise.

A good diet and regular exercise can help us to relax and get better sleep. And the opposite is also true: an unhealthy diet and lack of exercise can stop us from sleeping well.

Avoid eating large meals close to bedtime. Try to also ditch the bedtime caffeine (like coffee), alcohol or nicotine if you can, because these are stimulants that make us more alert. Stimulants are a common cause of sleep problems.

The general advice is to avoid stimulants 1 to 2 hours before bed. Try it and see if things improve.

Looking after your gut health with CKD

by Costanza Stocchi

Gut health is a hot topic in the wellness world at the moment, and not without reason.



disease, keeping your gut healthy can support your overall health, help you to maintain a healthy weight and promote a nutritious diet, things that have an overall positive impact on kidney health.

So how can you boost your gut health?

Eat plenty of fibre.

Fibre is what our very own population of gut bacteria feeds on, so it makes sense that we would nourish it as much as possible.

Fibre is mainly found in fruit, vegetables, and grains, so an easy way to include enough fibre in your diet is to try and meet your 5-a-day goal for fruit and vegetables: try to prioritise kidney-friendly options when choosing high-fibre foods, especially if you have been told to limit your potassium intake. For example, boiled broccoli, cauliflower and colourful lettuce are better options than aubergines, okra, spinach and mushrooms from a kidney perspective.

It seems that a healthy gut can positively influence other organs – including the kidneys.

Most people don't know that our gut is home to trillions of different microorganisms – bacteria and viruses that are impacted by the food that we eat, the levels of stress in our life, the quality of our sleep and our exercise levels.

A healthy population of gut bacteria does much more than promoting a healthy digestion: it works in controlling the levels of inflammation in our body and in boosting our immune system. Whilst we don't know if these benefits are enough to help delay the progression of chronic kidney

Whole grains are a low-potassium, kidney-friendly staple to include in your diet, and should make up at least one third of your plate. A bowl of whole grain pasta has more than twice as much fibre as the same quantity of white pasta, so swapping to whole grains (brown bread instead of white, brown rice, quinoa, spelt or barley) can double your daily fibre intake and keep your gut bacteria thriving.



Keep your diet varied!

Variety is the spice of life, and the known secret to keeping our gut bacteria healthy. Some researchers have shown us our gut bacteria love having up to 30 different types of plant-based foods a week. Try to keep your diet varied by making easy swaps - choosing mixed leaf salads, mixed vegetables, mixed beans or varying

your staples between wheat, rice, maize, potatoes, barley or spelt.

You don't have to get to 30 plants a week – it is an ambitious target and it can be difficult to keep track - but striving for it can improve your digestive health.

An easy way to include variety and fibre into your diet is to swap some of your meat, fish, chicken or eggs for vegetarian sources of protein, like chickpeas, lentils, beans and tofu. Be mindful of kidney beans as they are higher in potassium, and try to choose canned pulses or to boil them well.

It can be overwhelming to try to optimise your gut health while navigating the dietary restrictions of chronic kidney disease, so our tip is to start with one or two small changes to your daily habits: maybe two vegetarian meals a week, a variety of low-potassium fruit and vegetables, or more whole grains.

Remember that the different parts of our body don't work in isolation: gentle movement, good sleep and low stress levels can promote a healthy mind and a healthy gut, both of which can help support your kidneys.

Organ Donation Week (ODW) 2023

Organ Donation Week is a week-long campaign that takes place every year, with the aim of raising awareness about the ongoing need for organ donors. Around 6,000 people across the UK are waiting for an organ transplant.



Our ODW table setup at Hammersmith Hospital

Although the law around organ donation has changed it still remains your choice. It is very important to “have the conversation”, to discuss your wishes about donating your organs with your loved ones.

Become a living donor: Across the UK, more than 1,000 people each year donate a kidney while they are still alive to a relative, friend or someone they do not know. A healthy person can lead a normal life with only one functioning kidney.

We are always pleased to hear about your organ donation stories.

Organ Donation Week will take place from Monday 18th September to Sunday 24th September.

Stop by at our tables in the Hammersmith Hospital foyer on Monday 18th and Thursday 21st September.

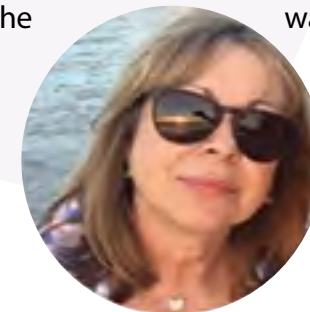
Sue Sandeman's decision to donate a kidney to her good friend Sarah was an easy no brainer

Deciding to be a donor was easy; Sarah needed one that worked and I had a spare one. It really was as easy as that. I had to have blood tests to check that I was a match and then various kidney function tests to check my kidneys were working well, but apart from visits to out-patient clinics and x-rays there wasn't much for me to do.



*Sue with friend and kidney recipient Sarah
Inset picture: Sarah enjoying a post-transplant holiday*

Once I'd made my mind up to do it the only people who needed convincing were Sarah, the person who wanted to make sure I was doing it for the right reasons, (I can't remember her title) and my son, he seemed to think it was risky, but the Transplant surgeon and transplant co-ordinator explained the whole procedure and process in detail. I knew what I was letting myself in for and to be honest it really wasn't that much of a big deal.



I was only in hospital for 5 days, the pain management afterwards was brilliant, far better than childbirth – and I'm being serious about that. I recovered fully within a couple of months and was back at work and exercising. Thirteen and a half years on and I wouldn't even know that I'd been through the operation. I don't feel any different and my body doesn't act any differently – everything healed up and life has carried on as it was before. The only real difference is that I still have my friend Sarah, alive and well. She doesn't have to dialyse; she has a good quality of life; her daughter has her mum and her husband has his wife.

To anyone considering becoming a donor, I would say “Do it!”

AGM of West London Kidney Patients' Association Notification & Agenda

West London Kidney Patients' Association's Annual General Meeting will be held on Thursday 26th October 2023 via Zoom at 6pm

Agenda

1. Welcome and Apologies for Absence
2. Minutes of the AGM held on Thursday 27st October 2022
3. Matters arising from last AGM
4. Declaration of Proxies held
5. Chair's Report on the year's activities
6. Financial report and Presentation of Accounts
7. Election of Officers and Trustees
8. Constitution and change of status
9. Any Other Business
10. Q & A

Only Members of WLKPA can attend the meeting. If you are already a Member and receive our Newsletter, kindly email chair@westlondonkpa.org or secretary@westlondonkpa.org stating you would like to attend.

If you have not already registered as a member of WLKPA, we will ask you to kindly fill in the Application form detailing your name, address, telephone number, email address and if you are Imperial College Renal & Transplant Centre (ICRTC) patient/carer/family/staff.

You could apply online at www.westlondonkpa.org/subscribe

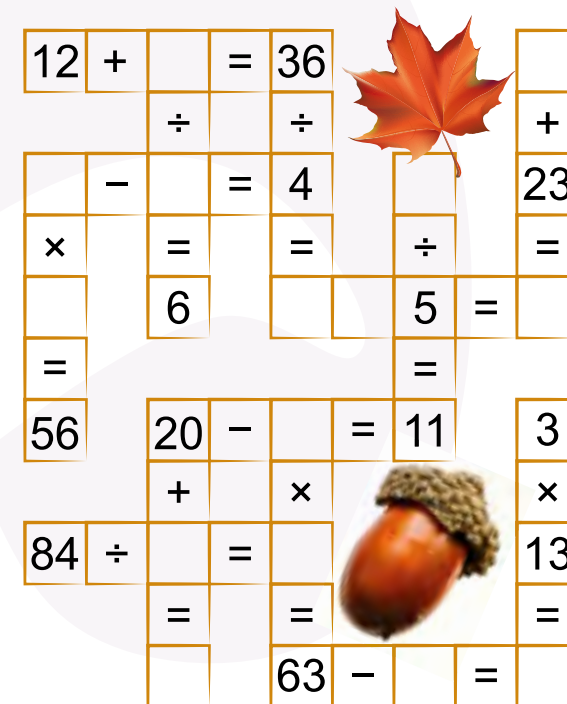
Reminder from the Renal Team

**ALL PATIENTS WITH CHRONIC KIDNEY DISEASE
AND ALL THOSE IMMUNOSUPPRESSED**

Please get the annual flu vaccine AND the pneumococcal polysaccharide vaccine

FOR CKD 4 AND CKD 5 PATIENTS

Please organise via your GPs the hepatitis B vaccine



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An autumnal maths puzzle

Can you fill in the empty boxes by working out the equations?

(Answers revealed on the website)

COFFEE
BREAK
PUZZLE

Imperial College Renal & Transplant Centre Contact Numbers

RENAL UNIT	TELEPHONE
Auchi Unit, Hammersmith Hospital	020 3313 6627
Brent Renal Centre, 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	020 3704 6519 / 020 3704 6510
Watford General Hospital	01923 217243
West Middlesex Hospital	020 8321 2543

Contact us: info@westlondonkpa.org
Or visit www.westlondonkpa.org

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