

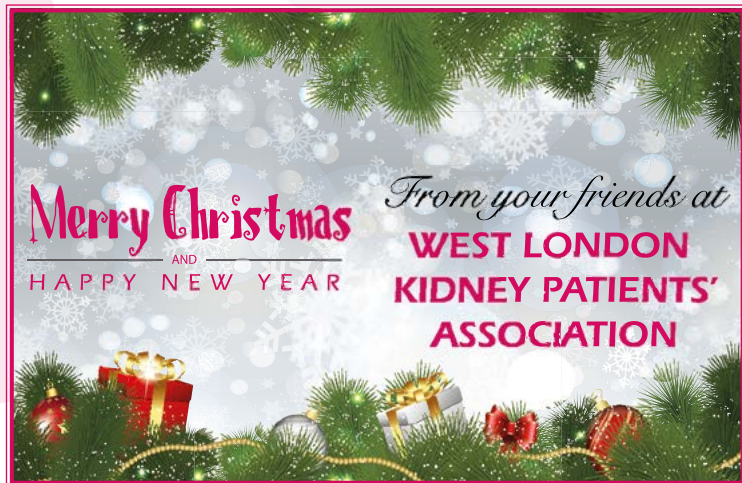


Supporting and working for  
kidney patients in West London

Registered Charity 275771

## The West London Kidney Patients' Association Newsletter

Winter 2021



Once again this year appears to have flown by. Hopefully by now, we have all been vaccinated and many of us will have had our 3rd primary doses. It's also important to get the flu jab. There have been warnings of "Super Colds" doing the rounds this winter so it would be wise to exercise caution when out and about over the festive period.

We wish to thank everyone who has sent donations from their personal fundraising activities and those of you who bought Christmas cards and sent donations with your orders.

If you have an interesting story you wish to contribute to future newsletters please get in touch. Our contact details are on the back page.

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## Allopathy, Alchemy and Elixirs – by Chetan Joshi

**Where would we be without family, friends and well-wishers? They all mean well but sometimes their “medical advice” could leave us literally high and dry.**

I had a very debilitating stroke way back in 2003. I still have tingling in my arm 24/7 “caused by nerve damage” so I have been told. While attending a reflexology class many years ago, a “well-wisher” suggested I rub pigeon blood on my arm. “No thanks” I politely retorted.

When I was diagnosed with CKD the following year, I was presented with all manner of suggestions to “cure” kidney disease from drinking beer to drinking hot water infused with herbs and spices. Being teetotal, the idea of drinking beer to cure kidney disease didn’t sit well with me. Besides, risking becoming dependant on alcohol on top of all my other woes at the time wasn’t very appealing..

So it came as no surprise to me when recently I was referred to a gastrointestinal specialist that a close family member “prescribed” aloe vera juice as an elixir to cure all ailments.

Having consulted with Lina Johansson – one of our renal dieticians, it turns out that although aloe vera is a natural

ingredient, the juice has ingredients added to it that may cause adverse reactions and these had not been tested specifically on kidney patients. And so the idea for this article germinated.

It is important for us all to understand that the medication prescribed to us by our kidney doctors has undergone stringent testing and approval processes to ensure its safety and efficacy. Any potential side effects that have been identified will be listed in the Patient Information Leaflet (PIL) that comes with the medication.

When it comes to alternative medicines whether traditional or suggested by a well-wisher, the safety aspect is often taken out of the equation and the element of risk needs to be considered.



Coming from an Indian/ Hindu background, throughout my life I have been exposed to the ancient system of Ayurveda that has been in existence for thousands of years. I do feel that I’m able to appreciate the benefits of both Allopathic and Non-Allopathic schools of thought.

Here in the west, we are used to taking a generic pill to cure most common ailments. A Paracetamol usually does the trick. However Ayurvedic medicine is based upon the individualised constitution of a patient. So a medicine that may be suitable for one person may produce undesirable effects for another. The fact that it is made with natural ingredients doesn’t necessarily make it safe for ingestion even if it’s an over-the-counter product.

I know for some, the prospect or reality of being on dialysis can increase the temptation to consider alternative medicines but please inform everyone involved in your healthcare of your decision before doing so.

Concerns over the use of harmful metals such as lead, mercury and arsenic, which pose grave health risks have blighted the reputation of Ayurvedic medicines. Nevertheless, it would be prudent to be wary of unqualified, diehard

enthusiasts who will always claim to know better.

The proliferation of cannabinoid (CBD) products for sale online and on the high street is another topic worth a mention.



Medical Marijuana has been noted to improve the condition of some

patients with certain conditions such as Parkinson’s. However it is important to know that some Cannabis based products can have severe neurological side effects such as psychosis.

The following paragraph is taken from an online article:

[https://journals.lww.com/co-nephrolhypertens/fulltext/2020/03000/the\\_nephrologist\\_s\\_guide\\_to\\_cannabis\\_and.15.aspx](https://journals.lww.com/co-nephrolhypertens/fulltext/2020/03000/the_nephrologist_s_guide_to_cannabis_and.15.aspx)

*“...consumers have easy access to a wide range of unregulated CBD products, some with inaccurate labeling and false health claims. Importantly, CBD may raise tacrolimus levels.”*

As kidney patients we all dream of a cure for this disease. In desperation, we may be tempted by claims and promises but please be mindful of falling prey to unregulated drugs and treatments.





**The Newbie's Guide to the Transplant Clinic  
at Hammersmith Hospital – by Chetan Joshi**



**H**aving recently attended the Transplant Clinic at Hammersmith Hospital, I was delighted when a friendly face tapped me on the knee as I was waiting to be called. It was a fellow patient who dialysed with me at Northwick Park Hospital years ago. She had recently had a kidney transplant and was there for her first clinic appointment.

**That got me thinking...**

The feeling you get when starting at a new school is similar to attending clinic for the first time. It can take some time to learn how systems work and operate. Some days when it can get busy in the clinic, we've all observed the frustration in the countenance of other patients and with the Covid rules in place, anxiety inevitably sets in.

So, here are a few points worth noting for all the new clinic patients. This list isn't exhaustive but gives a general overview of how things work and what to expect :

- If you are driving to the hospital, the car park is at the rear of the hospital in Wormwood Scrubs Car Park accessed by Artillery Lane. Please do not use staff car parking bays.
- It is advisable to use the RingGo app on your phone to pay for parking. You will need to register your car (model, colour, number plate) and link your credit/debit card the first time you use the app.
- Allow enough time for your appointment (roughly two hours but this can be longer on busier days). The app will send you a reminder if you wish to extend your parking time.
- Mobile phone coverage isn't great within the hospital (some mobile networks are better than others).
- Renal Outpatients and Main Outpatients are close by but they are NOT the same.
- When you arrive, you will need to have your name checked off at the door and have your temperature taken. You may then be guided where to sit while maintaining social distancing.
- Only patients are allowed in the Renal Outpatients waiting area.
- You will be called for Observations (Obs) Blood pressure and weight
- You will be called by the Phlebotomists for blood tests
- You will be called and seen by one of the doctors or a member of their team to discuss your condition
- The above three points may not always happen in this sequence**
- There are a number of places around the hospital where you can buy food and drinks. Follow signage to find the hospital Restaurant.

Above all else patients are encouraged to have some patience especially during busy times when there may be a shortage of staff. The fantastic staff are always doing their best to make sure your appointment goes as smoothly as possible. If you identify areas for improvement, please get in touch with us at [info@westlondonkpa.org](mailto:info@westlondonkpa.org) or submit a slip in a comments & suggestion box that may be available around the hospital.





## The Fight Against Covid 19 – by Dr Andrew Frankel

**The Covid 19 pandemic has had significant impact on people with kidney disease who are at a greater risk both of infection and of suffering a poor outcome from the infection. However, over the last 18 months there have been significant advances in relation to many aspects of this disorder including a better understanding of how to reduce the risk of spread, effective treatments and in relation to the development and implementation of a vaccination programme to protect people from Covid 19.**

In order to reduce risk of serious illness one needs to have an immune system that is primed against the Covid 19 virus. This occurs after infection, but is also effectively achieved by vaccination which mimics an infection and allows the immune system to develop significant anti-Covid 19 activity without suffering the effects of a real viral infection.

There is a considerable amount of misinformation present on the Internet and indeed in certain news publications and it is very important to dissect out the facts. One key message I would give all people with kidney disease looking for information on vaccination is to only use accredited sources of information and [Kidney Care UK](#) is an excellent resource to go to.

Vaccination can never provide 100% effectiveness at reducing the risk of infection and significant illness but it does provide exceptionally good protection. The

problem has been that people with kidney disease are less likely to fully respond to vaccines. People on dialysis may not mount a maximal response to vaccination and this is particularly so in people who are being treated with immune suppressing drugs to manage either their kidney disease or to maintain a kidney transplant. It is important that people with kidney disease on immunosuppressive drugs do not alter their treatment as the risks of this are of either loss of kidney transplants or acceleration underlying kidney disease.

It is because of the suboptimal vaccine response that certain groups, including those who are on immunosuppressive drugs, are recommended to have three primary doses of the vaccine rather than the two for everyone else. In addition, all people will need to have a what is called a booster dose to further augment the response to the

vaccine, usually at around six months after the last dose. It is most likely that we will see the implementation of an annual booster thereafter in the same way we currently have vaccination once a year against flu.

There is a considerable amount of speculation around the appearance of antibodies following vaccination. These are proteins in the blood that directly and specifically bind the Covid 19 virus thereby facilitating the removal of the virus. We know that antibody responses to vaccination vary and that they are reduced in people on dialysis and also in people on immunosuppressive treatment. What is not known is the implications of the variable antibody response. This is important because when one is exposed to either a vaccine or the Covid 19 virus the response is much more complex and not only confined to the production of antibodies. Vaccination also can stimulate what is termed cellular immunity which has ability to recognise Covid 19 and augment an immune response as well as directly killing virus infected cells.

We are working in a unit which is leading on trying to gain a greater understanding of the effectiveness of the vaccines in regard to reducing infection rates and ill health. We will need to observe over time what happens to people who have been vaccinated both in relation to their

antibody response but also to their subsequent reaction to Covid 19 infection. Consultants from Imperial have made a major contribution to this work and I also want to recognise the work that the entire renal team undertook to ensure that our patients received vaccinations at the appropriate time.

The key message therefore is that as a kidney patient you ensure that you have received the recommended vaccinations appropriate for your kidney disorder and treatment. If in doubt you should ask your treating clinician. You should still be vigilant about behaviours that help to reduce infectivity and advice on this can be obtained from the [KCUK website](#).

We are approaching the point where we will have an effective means by which we can reduce infection and certainly reduce harm caused by that infection. We will learn to live with Covid 19 without significant limitations to our life that we have seen over the last 18 months. I also believe that lessons that have been learned in relation to infection control on dialysis units, the development and rapid rollout of vaccination programs and the development of new treatments will also serve to provide significant benefits to all patients and particularly kidney patients in the future.

## Ode to your kidneys

After a recent shout-out over social media for newsletter contributors, a talented poet (and transplant patient) by the name of Helen Jennings got in touch and sent us one of her poems. We're sure there are many more talented individuals amongst us. Whether you're a poet, artist, chef, musician, sports enthusiast, singer, dancer, magician... whatever skills or interests you may have, if you'd like to share it with us, please get in touch.

### Do you know what your kidneys do?

*Do you know what your kidneys do?  
Ever really thought about the real you?  
Two small organs, shaped like beans  
Do you ever think what they really mean?*

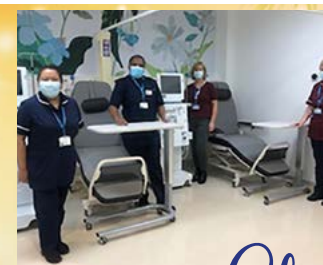
*They filter fluids, 200 litres every day  
Produce vitamin D, but not vitamin K  
Manufacture Epo, to produce red cells  
Without it anaemia makes you feel unwell*

*Balance your phosphates, we need to take binders  
Make little notes as constant reminders  
Increased potassium, a #CKD patients fear  
Balancing diet can reduce us to tears*

*Salt, the constant enemy within  
Increases blood pressure, so throw it in the bin!  
A constant fight to maintain homeostasis  
I can see the bewilderment on so many faces*

*So do you really know what your kidneys do?  
You need to think about the real you  
Look after your kidneys before its too late  
As one day they may just seal your fate!*

©Helen Jennings June 2021,  
originally published March 2018



*Merry Christmas and  
a happy new year from  
the Dialysis teams*



*We all wish our patients, their families and carers  
a very happy festive season and best wishes for 2022  
- Staff at Northwick Park Hospital*





## Kidney-friendly Christmas Feast

– by **Costanza Stocchi**

**If the supermarket mince pies and freezing cold have not given it away yet, Christmas is just around the corner.**

**W**hen we think of Christmas, a dinner feast and glasses of mulled wine is what comes to mind for most of us, along with time spent with friends and family.

Food is more than just fuel: it is a social activity, a reunion, sharing and experimenting in the kitchen: this is more obvious when celebrating the holidays, cooking together while embracing the relaxation and leaving the past year behind.

While the (over)indulgence may seem daunting if you have kidney disease, or if you are on dialysis, there are still ways to enjoy the festive period and all the seasonal goods it has to offer. You can be sensible with your diet by focusing on two main things: potassium and fluid. Try limiting your high potassium foods to small quantities and spreading out your fluid throughout the day to enjoy the Christmas period safely.

### **Can I eat mince pies, christmas pudding or fruit cake?**

- Yes! If you tend to have a high potassium level, try to have only 1 small portion in a day, so either a bit of Christmas pudding, a small piece of fruit cake, or 1 - 2 small mince pies. Try not to have more than 2-3 portions of these over the Christmas period

### **What traditional Christmas foods can I have? Do I have to miss out on the Brussel sprouts?**

- No! Boil brussel sprouts in plenty of water, and try to limit these to 5-6 in a day.
- If you plan on cooking or bringing a dish, why not make something delicious AND kidney-friendly? Kidney Care UK has put together a mix of Christmas recipes that are low potassium, low phosphate and usually low in salt, which you can find online or by asking the dietitian at your dialysis unit.

### **Can I drink?**

- Yes, in moderation. If you are taking medication and feel unsure, check with your doctor or pharmacist. We normally advise to limit to 1 or 2 units a day – this is about a pint of beer, two glasses of wine or two glasses of spirits. If you have a fluid restriction, take this into account as well. Try to choose low potassium drinks, like white wine, port, sherry, spirits and liqueurs in small quantities, limiting cider, lager and red wine, which are higher in potassium.



### **Dietitian-approved Renal Friendly Christmas menu:**

#### *Starters:*

**Prawn cocktail  
Brie and Filo pastry parcels  
Vegetable quiche**

#### *Mains:*

**Roast turkey with a small amount of stuffing, or**

**Steak and ale pie**

#### *Sides and trimmings:*

**Parboiled roast potatoes**

**Boiled brussel sprouts – 5 or 6**

**Pear and cheddar cheese salad**

**2 or 3 small pigs in blankets**

#### *Dessert:*

**Trifle, sorbet, pavlova, crème brulee or crumble**

**– all low in Potassium**

**Small portions of Christmas pudding, or**

**Small portion of gingerbread log, or**

**1 small mince pie**

#### *Extras:*

**2 satsumas**

**2-3 small chocolates**



## Improving renal patients' experience

– by Aisha McKenzie

**Renal Rapid Assessment Unit is a specialist ambulatory care department accessible to our renal patients who require urgent treatment or medical attention, which is not life threatening.**

The unit has previously functioned as a walk in service to renal patients. In response to the pandemic, the service provision has adopted an appointment based service. Patients are encouraged to ring the department if they are unwell to be triaged by a member of the team, and an appointment is made accordingly.



From L to R: Aisha Tamika McKenzie RAU Sister, Paivi Nieminen RAU Sister, Oshini Shivakumar Renal SpR, Imara Knight-Robertson RAU Administrator and Mossamat Akter Renal SpR.

During the month of July, the team participated in the Walk for Wards 21 fundraiser hosted by Imperial Health Charity. The idea to participate initiated

as a fundraising venture to install a water fountain at RAU. Renal transplant patients are encouraged to maintain adequate hydration. This is usually challenging for patients waiting in the department. There was room for improvement in our service provision. We wanted to help improve the patient experience by providing adequate hydration.

A brief discussion with Consultant Dr. Neill Duncan resulted in prompt registration of the team under the sobriquet "RAU Rovers". The RAU staff includes Imara Knight- Robertson, Paivi Nieminen, Michelle Zagote and myself Aisha Tamika Mc Kenzie. We were joined by other members from the renal family. The enthusiasm shown by all team members evolved into an overwhelming response to our fundraiser page, with the West London Kidney Patients' Association (WLKPA) being one of our major sponsors.

The RAU Rovers are thankful to the WLKPA for convening and collaborating a partnership. We have since embarked on an extended project to do further enhancement to the RAU environment. So far, we have placed some colourful Artwork sourced from Imperial Health Charity. This has added exuberance to the department. With the partnership, RAU Rovers have been able to purchase the water fountain and are awaiting its delivery. We have purchased comfortable chairs for the department. Now, we have a

scale to weigh patients in RAU, and we are still working towards the purchase of an ice machine for the Auchti Haemodialysis Unit. We are collaborating with the renal wards to fill Renal Community Chests for patient entertainment on the inpatient wards.

The support of the WLKPA has enabled RAU Rovers to make progression in our environment project. Their willingness to work with our team to improve the experience of renal patients is hugely worthy of praise.

From L to R: Paivi Nieminen RAU Sister, Imara Knight-Robertson RAU Administrator, Aisha Tamika McKenzie RAU Sister and Dr. Neill Duncan Renal Consultant and Clinical Dialysis Lead







## Renal Counselling & Social Support Team

The Renal Counselling & Social Support Team at Imperial College Healthcare Trust are continuing to support our patients through these transitional times. As Covid 19 restrictions are being lifted, we are mindful that for many of our patients this may be a worrying and difficult time.

We will be continuing to offer telephone counselling and social support. Now that restrictions have changed we are also able to see patients for face to face booked appointments in the hospital setting if required.

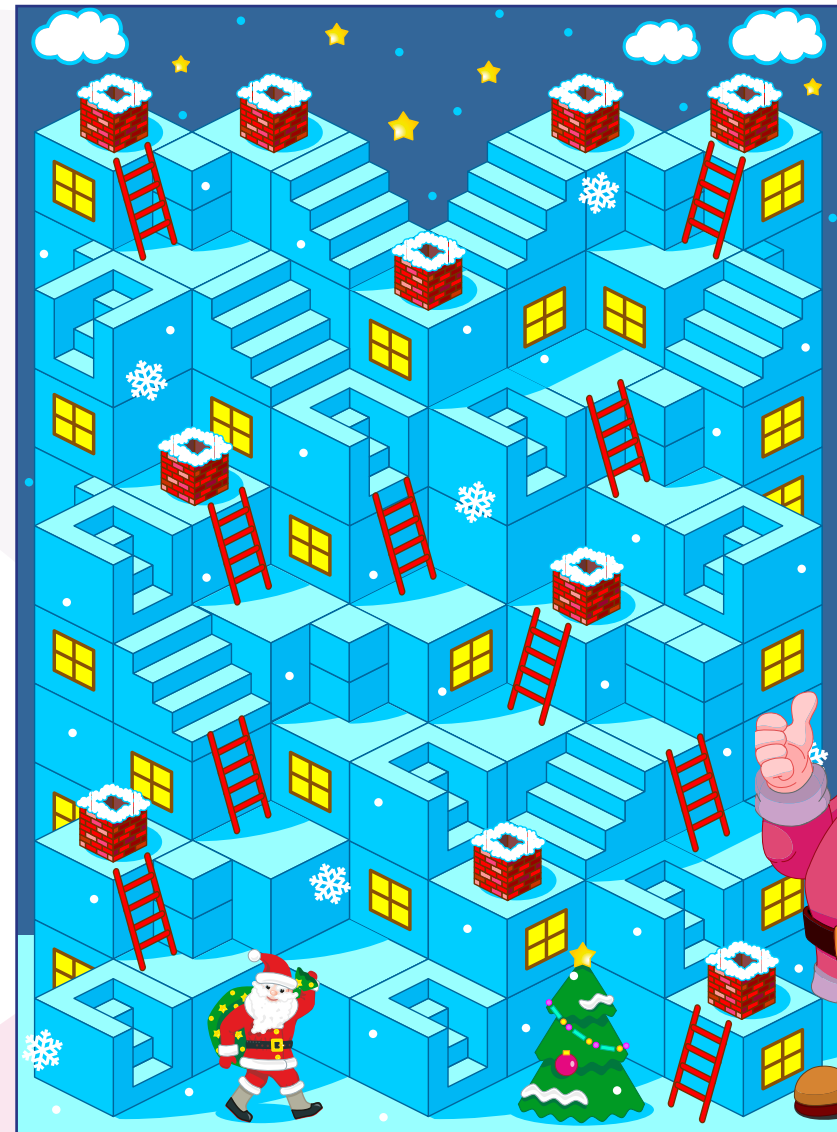
Sheila Goddard Renal Counsellor took part in a fund raising hike for Climbing Out charity and raised £433.00. Well done Sheila! Climbing Out is aimed at those who have had a life changing illness, accident or Trauma. Sheila is happy to provide more information for anyone who may be interested in participating. Anyone can self-refer for the course, the application form can be found on the Climbing Out website.

Finally, do you know that if you are on certain benefits or on a low income you may be able to get a discount of up to 50% off your water bill? Contact your water supplier to find out about the Waterhelp scheme.

The warm home discount scheme provides you with £140 credit on your energy bill if you are on a low income. The scheme opened in October. The application process is really quick. You can apply online on your energy supplier website or by calling your energy supplier.



*Season's greetings from the Renal Counselling and Social Support Team*



**Can you help Santa deliver presents through the chimneys? (Don't miss any!)**

**Use the stairs and ladders but for Elf'n' Safety reasons don't let him jump or climb walls.**

**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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