

The West London Kidney Patients' Association Newsletter

Autumn 2021

We hope you have had an enjoyable summer and have been able to meet up with family and friends.

It is still important that we as Extremely Clinically Vulnerable individuals, even after two vaccinations, keep ourselves safe by

- meeting people outside or keep indoor areas well ventilated
- wear a face covering in crowded places
- wash our hands regularly
- do not touch our faces
- use hand sanitiser
- take regular lateral flow tests

Kidney Care UK (www.kidneycareuk.org) continue to update COVID-19 guidance and information for patients with kidney disease. *The OCTAVE study and other research will guide

JCVI's guidance on the rollout of 3rd vaccine and we expect an announcement very soon.

**quote from KCUK website on Recent Updates dated 25 Aug 2021*

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My Experience of Peritoneal Dialysis (PD)

by Ray Martin

The WLKPA newsletter recently featured the great work being done in Peritoneal Dialysis (PD) by the Renal Home Therapies team.



PD cleans a patient's blood within their abdomen with dialysis solution. There are two types

- **Automated Peritoneal Dialysis (APD)** uses a machine called a cycler that automatically fills and drains the abdomen (exchanges) with dialysis solution while a patient is asleep. **Continuous Ambulatory Peritoneal Dialysis (CAPD)** works through a series of manual exchanges during the day. Both avoid the need for a patient to attend hospital for their dialysis.

I started PD a few months after being admitted to Hammersmith Hospital with end stage renal failure in 2005. Whilst I was in hospital a PD nurse explained to me how Peritoneal Dialysis worked and the independence it offered compared to the hospital administered Haemodialysis.

At the time I was working for BT commuting every day into central London. I was particularly worried how my job might be affected by having to attend hospital probably 2 or 3 times a week.

APD appeared to solve that particular issue and the PD team at Hammersmith Hospital provided invaluable tuition and support preparing me for the change over. A first step was a minor operation to insert a catheter into my abdomen.

A few weeks later a cycler, packed in its very own travel case, was delivered to my home. A PD nurse spent an afternoon teaching me how to set it up ready to start therapy. Today, as an additional resource for patients, excellent PD tutorials can be viewed online at YouTube.com.

At first setting up the cycler was a bit daunting without the support of a nurse standing nearby. However, by remaining calm and persevering I mastered the process after a few days. I was also usually able to sleep well, despite the machine being situated close

to my bed. Every morning, once therapy had ended, I began the routine task of disconnecting and disposing of used PD tubes and dialysis solution bags.

Being on PD also meant clearing a large space in my house to store approx. 40 boxes at a time most containing dialysis solution bags. Supplies were delivered to my home in a very large lorry once a month.

The main disadvantage of PD is the risk of infection. Hand hygiene is therefore extremely important to help prevent this occurring. PD nurses spoke to me so often about the importance of hand hygiene that washing my hands and also using an antiseptic gel became second nature.

I was off work from BT for roughly 3 months and initially returned on a part time basis. A plan for my return to work had to be agreed between myself and line management. I asked my union representative to sit in on these meetings as well. He gave me advice and negotiated some improvements on my return to work agreement. He did a similar job when I returned to work following my kidney transplant a few years later.

During my 4 years on PD, I often worried about sustaining an accidental injury that could incapacitate me for a period of time. For example, a sprained ankle would have caused a serious problem managing daily PD. I avoided taking unnecessary risks and generally took extra care in my daily routine.

PD enabled a greater freedom with holiday destination. I stayed in the UK and booked delightful holiday cottages. The type of location had a bit more privacy and had the room for my cyclist and storage of dialysis solution boxes needed during my stay.

My most poignant memory was the holiday I had in Dorset with my mum in the summer of 2008. She was very ill and just a few weeks later passed away in a hospice. PD made it possible for me to share that final holiday with her.

PD finally ended in July 2009 when I received a kidney transplant at Hammersmith Hospital. PD will not be for everyone, but it suited my personal situation at a particular time. I would certainly consider PD again should the need arise in the future.

NKF HOME DIALYSIS PEER SUPPORT SERVICE



**WOULD YOU LIKE SOMEONE TO
TALK TO AND EXPLORE THE OPTION
OF DIALYSIS AT HOME?**

**Speak to one of our trained
home dialysis peer supporters
based across the UK.**

**Giving short-term practical, emotional and social support
to people with kidney disease, their families or carers.**

**For more details contact the
National Kidney Federation FREE Helpline
0800 169 09 36**

www.kidney.org.uk

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Notification & Agenda of West London Kidney Patients' Association's Annual General Meeting

West London Kidney Patients' Association's Annual General Meeting will be held on Thursday 21st October 2021 via Zoom at 6pm

Agenda

1. Welcome and Apologies for Absence
2. Minutes of the AGM held on Thursday 29th October 2020
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

Dialysing at Home: My Choice

by Adrian Capitan

The first step to empowering patients is to embed shared decision making and self-care at the heart of kidney services. This will enable patients to have more insight into managing their own condition, improving their ability to make informed choices, gaining greater control and improved health to best suit their own life (NHS England, 2010).

Photou Hiribis is a 75 year old, with polycystic kidney disease (PKD), a form of hereditary chronic kidney disease (CKD) that reduces kidney function and may lead to kidney failure. Dialysis or a kidney transplant is necessary to stay alive. She has been dialysing for more than 3 years and think dialysing at home is the best decision she ever made.



Photou is being supported by her husband but she does everything from lining the Haemodialysis machine, preparing the pack, putting herself on/taking off the machine. She has an alarm bell beside her to press when

she needs something while on dialysis and her husband comes almost immediately. "I really like it. The control over my treatment is the reason why I chose Home Haemodialysis," says Photou.

Most patients who dialyse at home have a greater understanding of their condition and treatment, with increased confidence and empowerment. They can also have a good appetite, stable weight, improved energy and a more positive mental state.

Photou says much of her success on Home Haemodialysis(HHD) is due to the training she did in NPH (Northwick Park Hospital) Dialysis Unit with the Shared Care/Self-care training team. If she had any trouble, she said the team would help her resolve it right away.

For Photou , HHD has meant regaining her normal life. "I would definitely recommend Home Haemodialysis. At hospital I was dialysing three times a week, have

to travel and wait for someone to finish. At home I do 4 to 5 times a week anytime I want. This made me feel better, I don't have the weekend build-up of waste and fluid."

THE FACTS

HHD can support NHS under immense financial strain and facing the largest workforce challenge in living history. Patients being able to dialyse at home can free up capacity and resources for other areas of patient care. Furthermore, since HHD costs up to £15,000 less per patient compared with in-centre dialysis, crucial funds can be reinvested into the NHS. This shift towards self-care would play a key role in meeting the ambitions of the NHS People Plan by prioritising innovation and delivering care in new ways to create capacity within the NHS (Milad,2021).

HHD would also enable dialysis patients to shield safely and dramatically reduce the risk of exposure to COVID-19 currently caused by the need to travel to clinics, wait for appointments and dialyse in-centre (NKF, 2021).

Progress on increasing the numbers of those treated at home has been slow – and now appears to have stalled. Data from 2019 shows that overall around 7%

of all dialysis patients dialyse at home; 2% are on HHD and 5% on Peritoneal dialysis. One of the key recommendations is that all adult renal units in the UK should reach a minimum prevalence rate of 20% of their dialysis population on home dialysis (peritoneal and home haemodialysis) by the end of 2024 (NKF, 2021).

MOVING FORWARD

NKF is embarking on a national campaign to increase home dialysis in the UK. The campaign will focus on the disproportionate impact Covid-19 has had on patients who dialyse in a centre. They have written to clinical leads of renal services and to all chairs of Kidney Patient Associations (KPA's) to request their support in encouraging more patients to dialyse at home.

For more information please visit: www.kidney.org.uk/home-dialysis-campaign & www.westlondonkpa.org

References:

National Kidney Federation. Home dialysis the advantages. 2021. www.kidney.org.uk/home-dialysis-the-advantages (accessed 23 August 2021)
Milad, J. Building dialysis back better: how can government ensure we get it right for dialysis patients? JKC, 2021.
NHS England. Improving choice for kidney patients.2010. www.england.nhs.uk/improvement-hub/wp-content/uploads/sites/44/2017/11/Improving-Choice-Home-Haemodialysis-Toolkit.pdf (accessed 23 August, 2021)

Oliver Connell – The OC Way Charity Cycle Ride

Our regular readers will recall the article about the Oliver Connell & Son Ltd Charity Cycle Ride in memory of its founder Oliver Connell who was a double transplant recipient.



above – Group photo of cyclists including Pat Connell, Oliver’s cousin and kidney donor

The 90 mile ride from the firm’s construction site at Trinity College, Oxford to their site at Addenbrooke’s Hospital in Cambridge raised £70,000. This was divided equally between West London Kidney Patients’ Association and the Lighthouse Club Construction Industry Charity which offers charitable welfare and support to the construction community.

The OC Way charity ride was a challenging event with rain and adverse weather to contend with, however the determination and mindfulness of why they were

taking part spurred the 22 cyclists on to the finish line.

We were happy to be there to greet them and personally congratulate them on their wonderful achievements.



above – Tom Connell, (Director, Oliver Connell & Son Ltd),



Receiving the cheque above from l-r
Roddy Walsh, (Senior Estimator, Oliver Connell & Son Ltd)
Sinead Whelan (Lighthouse Club)
Tom Connell, (Director, Oliver Connell & Son Ltd)

Receiving the cheque below from l-r
Roddy Walsh, (Senior Estimator, Oliver Connell & Son Ltd),
Tom Connell, (Director, Oliver Connell & Son Ltd),
Sarah Ilic, (Secretary, WLKPA) & Sarita Khurana (Chair, WLKPA)



Diet trends – why they should be avoided by Costanza Stocchi Renal Dietitian

The Ketogenic (or “keto”) diet and intermittent fasting have become very popular in the last few years – mainly because of their successful (but short-lived) effects on weight loss. Despite their reputation in magazines or on TV, these trends are not sustainable diets for people with kidney problems – let’s see why.

What are they?

The keto diet was developed in the 1920s with the aim of helping people with epilepsy. It revolves around eating lots of fats and very small amounts of carbohydrates – this means restricting foods like pasta, rice, potatoes, corn, but also fruit, vegetables, beans and lentils: imagine a plate that is around three-quarters full of high-fat foods: think cheese, butter, eggs, avocados and cream.



Intermittent fasting consists in fasting for several hours a day – limiting your “eating window” to only 8 hours a day or having a few days of not eating every week.

Are there benefits for people with kidney disease?

A very low calorie ketogenic diet has shown some benefits in overweight people with mild kidney disease – including some recovery of kidney function. Here, by “very low calorie” we mean between 450 and 800 calories per day – around 1/3 or less of a normal day of eating for most people, an amount too low for our bodies (and brain!) to sustain for long.

Unfortunately, there are currently no studies exploring these diets for people on dialysis or with advanced kidney disease and there is only some very early stage, but promising, research on the impact of keto and fasting on polycystic kidney disease. So far this is limited to animals, so we might have to wait a while before seeing positive results in humans.

Are there risks?

Both diets are very restrictive and have many downsides. Eating for 8 hours a day only could result in not

eating a big enough variety of foods, especially fruit and vegetables, and not eating when we are hungry if it is not the “right time” could put us out of touch with our body’s needs and hunger signals.

A strict keto diet could also result in eating too much “unhealthy” food – bacon, sausages, cheese... Not the best options for your kidneys as they are high in salt and can increase levels of LDL (or “bad”) cholesterol, raising the risk of heart and circulatory problems.

Before going on a “fad” diet...

1) Speak to your renal dietitian

Neither are healthy, balanced diets: changing your diet to a keto or fasting regime is not a change you should make alone. Discuss it carefully with your renal dietitian and your doctor to understand the risks, get support and most of all set an end point! These diets are not forever - they eliminate lots of healthy food, set unrealistic boundaries around eating and might take away the enjoyment and social aspect of food.

2) Think carefully of the risks!

If you have diabetes, neither of these diets will be suitable for you: not eating for a long time might make your blood sugar drop, especially if you are taking insulin. If you have type 1 diabetes, a

ketogenic diet could result in very high blood sugars and diabetic ketoacidosis, a serious medical emergency. If you are on dialysis, neither diet is indicated as they might not give you the energy and protein your body needs.

3) They are not an easy fix!

These diet trends require a lot of preparation – including cooking, grocery shopping, meal planning – and very little flexibility. It can take days to weeks for your body to start using fat as fuel efficiently, so a ketogenic diet does not have any “cheat days”, and could be very difficult to sustain. If you are physically active, going to work or studying, intermittent fasting can make you feel low in energy throughout the day, especially if you are not eating until the afternoon.

In conclusion...

As you can see, these hyped “fad” diets are not recommended for people with kidney problems. The best thing to preserve your health is to eat a healthy, Mediterranean-based diet: eat a variety of food, mostly plants (fruit, vegetables, whole grains) and, if you do want to improve your diet, think first about making a few small, but sustainable, changes at a time – like having meat-free days or eating vegetables with every meal.

Christmas Cards 2021

We will only be selling our packs of Christmas cards through the post again this year. A variety of appealing designs have been carefully chosen and hopefully you will see some you like.

The Christmas card leaflet and order form should accompany this issue but if there isn't one or you know someone else who would like to order some packs then the form can be downloaded from our website at www.westlondonkpa.org/christmas-cards-2021. We will start posting orders out at the beginning of November. If you need yours earlier than that please call Sarah on 07988081295.



Walk For Wards 2021

Warm Congratulations to Dr Neill Duncan, RAU Rovers, their junior family members and dogs! Dr Neill Duncan and his wonderful multi-disciplinary team of nurses and doctors walked to raise funds for a water fountain and ice machine for the RAU (Rapid Assessment Unit) at Hammersmith Hospital. They raised £2,844 which was 142% of their target and WLKPA will match this. The water fountain and ice machine will be used by Auchu patients and RAU attendees which will be most welcome and a necessary addition.



Important Notice for Renal Clinic Patients

The Renal Outpatients staff need patients to attend their allocated appointments on time; not more than 10 minutes earlier than their allotted time; to come alone unless absolutely necessary that they have a family member or carer with them so that the physical distancing can be maintained in the waiting area.

THIS MEASURE IS FOR EVERYONE'S SAFETY.

It is so very important, in fact vital, that we, as Extremely Clinically Vulnerable people, continue to be cautious, wear masks in crowded or indoor places, wash our hands and sanitize them regularly and keep socially distancing.

Coffee Break Puzzle

Can you find the eight autumnal words in the grid below?

AUTUMN HARVEST
 CHESTNUTS HIBERNATE
 CRUNCHY LEAVES
 HALLOWEEN VACCINE



Some of the unused letters spell out a hidden message.

— — — — —
 — — — — —
 — — — — —

WLKPA support given so far this year = £17,921.39

Annual Crisis Fund
Dermatoscope
Postal Capillary Blood Test Pilot
Covid-19 Research Test Kits
Pilot Screening for Starter Dialysis Patients for Latent TB
Replacement TVs for St Charles and West Middlesex Dialysis Units
Chairs for patients waiting room at Watford Dialysis Unit

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 currently changing, we are mindful that for many of our patients this may be a worrying and difficult time.

We have been offering our support through telephone counselling and social support throughout the Pandemic. This seems to have worked well as it provides a flexible means of communication that feels safe in the comfort of the home. Now that restrictions have changed we are now able to see patients for face to face booked appointments in the hospital setting. However, we will continue to offer telephone support for those who prefer this.

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

We also wanted to make you aware of a charity called Climbing Out which offers a five day fully funded outdoor activity programme for anyone, aged 18 and over, who has experienced a life changing illness, injury or trauma. The aim of the course is to help rebuild confidence, self-esteem and motivation.

Anyone can self-refer for the course, the application form can be found on the Climbing Out website <https://climbingout.org.uk>.

Sheila will be taking part in a fund-raising hike in October to raise money for the charity.

Finally, this last year has been one of considerable financial strain for many people.

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 opens in October 2021. The application process is really quick. You can apply online on your energy supplier website or by calling your energy supplier.

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
Or visit www.westlondonkpa.org**

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

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