



This year seems to be much more positively charged than the previous couple of years. As Covid restrictions ease and life returns to a state of normality, we all still need to remain vigilant against the risk of infection. Patients with weakened immune systems are being invited to have a 5th Covid vaccine.

The Nation enjoyed an extra long break over the Jubilee weekend to mark Her Majesty the Queen's 70 years of service. Our dialysis patients and staff joined in the celebrations too. They had a lovely time as can be seen in the pictures on pages 8 & 9. WLKPA were proud to fund the Platinum Jubilee celebration's refreshments and decorations for the dialysis units and renal wards so that patients who dialysed over the bank holiday could have a jubilee tea party.

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Staying Well with Kidney Problems

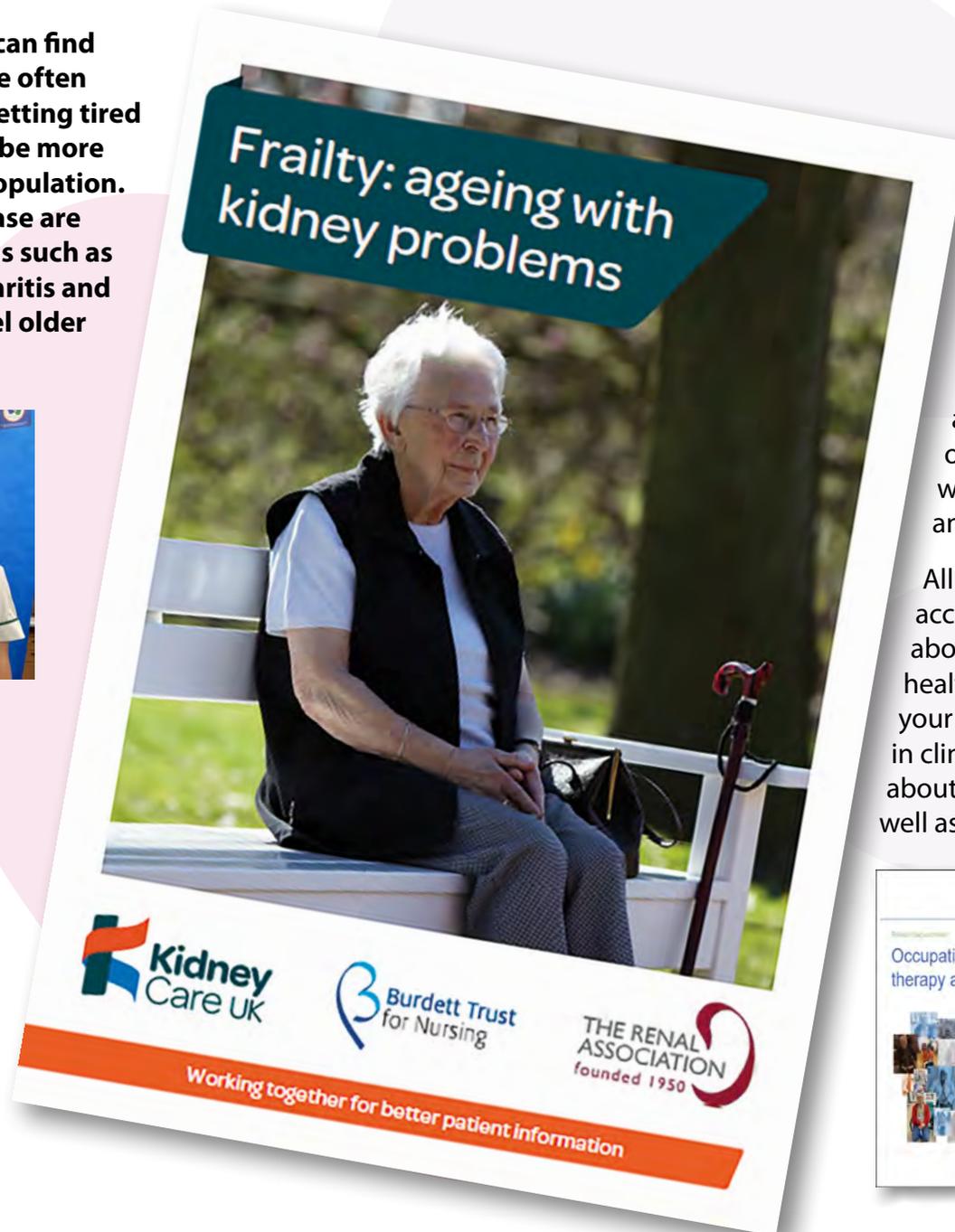
by – Jackie McNicholas

People with kidney problems can find that health issues that are more often seen in older people, such as getting tired easily or mobility changes can be more common than in the general population. Some people with kidney disease are also managing other conditions such as diabetes, heart failure and arthritis and these can also make people feel older than they really are.



The renal (kidney) frailty team – (l-r) Neil, Jackie, Zai

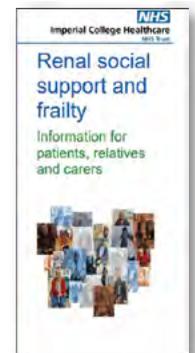
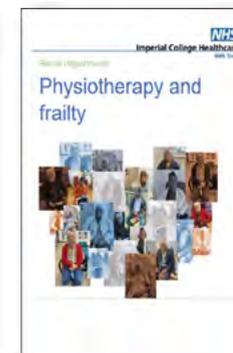
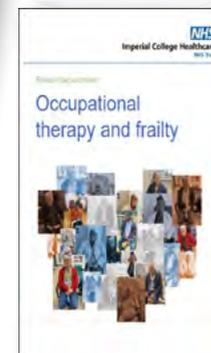
The renal (kidney) frailty team based at Hammersmith Hospital comprises of Physiotherapists, Occupational Therapists and a Renal social support worker (and others) who have noticed that our patients are needing more advice and support when they meet them on the kidney wards. From some of the improvement work that we



Michelle Delon – Renal Social Support Worker

have been doing over the last couple of years as part of a Frailty project, the team have been able to develop some booklets that patients and carers can use to help maintain your independence and safety at home. The Renal social support leaflet outlines the issues that Michelle can help with as we appreciate that kidney treatments and daily life can be challenging at times.

All the leaflets explain their service and how to access further support. Sharing your concerns about coping with your physical and mental health (other than your kidneys) is important for your team to know. The leaflets will be available in clinics so please ask your nurses and doctors about them so that we can support you to stay as well as you can.



At Home with Dialysis by – Kasonde Konie

Meet Nexxie: short, stout and simple in appearance, which belies an incredible lifesaver.



I love life and like living it to the full. Home dialysis has allowed me to take back control and manage CKD instead of letting it manage me.

That is why I am happy to join in leading the cheer for home dialysis and why I became a National Kidney Federation Peer Supporter. I am also speaking about it at a NKF parliamentary session in July.

So, what's so good about it?

The # 1 BENEFIT –
Self management/ care

If you have CKD and wish to live better for longer, then you must overcome 3 major challenges – I call it mastering the 3Rs of RRT : (stay on the) **right** diet, (have) **regular** exercise and (find ways to) **reduce** anxiety for better sleep.

Being at home, I have learned to be responsible for these 3 aspects and partner with my medical team in the care of my health.

What's not so good ?

The #1 BANE – high cost in time and money

After “Naomi”, my kidney transplant of 14 years also failed, I am dialysing at home for the second time with Nexxie, NxStage's home dialysis machine.

I've lived with chronic kidney disease (CKD) for over 20 years. It's been a rollercoaster of a ride. I have gone from totally clueless about CKD and dialysis to confident expert self-carer.

Unlike other machines, Nexxie is labour intensive and time-consuming. It takes over 6 hours to make a dialysate batch, 30 minutes to set up the cartridge (lines). That's a lot of electricity and water usage which is a concern in this current cost of living crisis.

I appreciate the quarterly reimbursement I receive from the hospital. Sadly, it just a drop in the ocean hence the NKF's campaign to secure suitable reimbursement and make home dialysis affordable.

What could be better ?

-BOOSTING support for home dialysis

When I was training for home dialysis, I learned that most are afraid because “what if something goes wrong”?



Hammersmith Home Dialysis Team from L to R Eden, Normandy, Kasonde (HHD Self-carer) and Adrian

Well, before I was allowed to go home, I had to be assessed and deemed competent as I dialyse alone. I am also armed with manuals for troubleshooting, 24-hour tech support and office/ out-of-hours clinical support

So, is home dialysis for you?

Home haemodialysis was again the natural choice for me for 3 main reasons

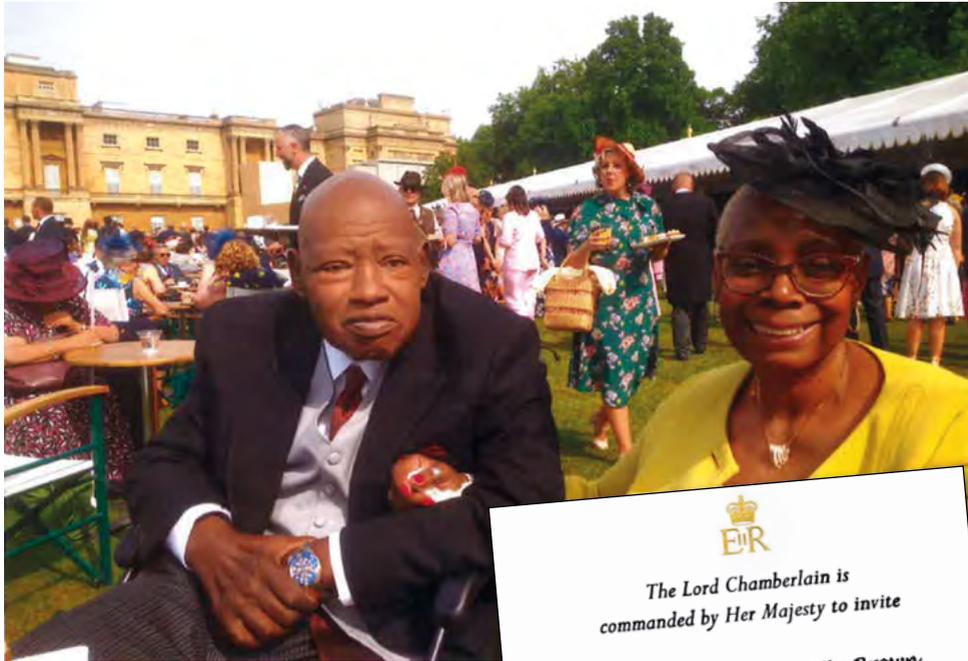
1. because I value my independence and work part-time.
2. I think it's the next best thing to a transplant when it comes to freedom of choice and flexibility- I choose when to dialyse.
3. Managing my condition, I have a better quality of life and that is priceless.

So if, like me, you want to be more independent, embrace living instead of just existing and ultimately move from dis-ease to ease so that you feel at home with CKD, then I highly recommend you consider it.

Kasonde - Administrator living with CKD



Neville and Rita's Party at the Palace – by Chetan Joshi



It's not everyday that we get to rub shoulders with members of the royal family. That's exactly what happened to Neville and Rita Brown earlier this spring.

Neville is a dialysis patient at Northwick Park Hospital where he has been on haemodialysis since 2018. His wife – Rita has enjoyed a long career working as a PA in the area of infectious diseases. To commemorate her retirement this year, Rita's (former) boss nominated her for a special recognition for the marvellous work she has done especially over the past couple of years.

The day of the garden party in the grounds of Buckingham Palace was unforgettable. The weather was perfect and everyone was dressed in their finest clothes to suit the prestigious occasion.

Kate – The Duchess of Cambridge was among the hosts along with Prince Edward, Earl of Wessex and his wife Sophie, the Countess of Wessex. The afternoon was filled with live music and an abundance

of delicious sandwiches, cakes and soft refreshments. Rita recalls how kindly they were treated by the staff. As Neville was in a wheelchair, they were assisted to front row viewing to see the Royals arriving.

Previously, whilst working full-time, Rita had to take Neville for dialysis in the evenings making it very late by the time they got home after dialysis. Now that Rita is retired, she is currently undergoing the training

required for Neville to be able to have his dialysis treatment at home. This will give Neville more flexibility to manage his dialysis with less visits to and from hospital. It will also give them more quality time together and they will be able to travel more with the portable dialysis machine.

If you want to discuss your dialysis options, speak with your renal doctor or nurse who will guide you to the relevant specialists.

Message from Sr Katie Tansey – Renal OPD



I would just like to say a huge thank you to the KPA for allowing me to buy 2 new wheelchairs and padlocks for renal patients.

I cannot express how great it is to have them here to help us get elderly and less mobile patients around the clinic.

So thank you once again.

Can I also just remind all our patients that masks **are essential** in renal OPD as our patients are extremely vulnerable.

I know the communications around mask wearing is confusing but we still need all patients to wear masks.

Also we still cannot allow relatives or friends into clinic as patients still need to socially distance so we only have enough seats for patients.

Please remember all Immunosuppressed patients should have a 5th vaccine – the covid vaccine hub at Hammersmith hospital is still taking walk-in's Monday – Thursday.

PLATINUM JUBILEE CELEBRATIONS



"Our patients wanted to say thank you to WLKPA for the lovely treat they had to celebrate and feel the spirit of our Jubilee celebration. As always, on behalf of Hayes Unit, thank you so very much."

Kerr Ward's Tea Party



De Wardener's Tea Party



"On behalf of the patients, thank you so much for your generosity and continued support, it is much appreciated",
West Midd



"Patients said thank you to the KPA. It was well received and appreciated." Brent

"Huge Thank you to WLKPA for funding the Jubilee celebrations. We have made the most wonderful memories."
Sr Helen Watts

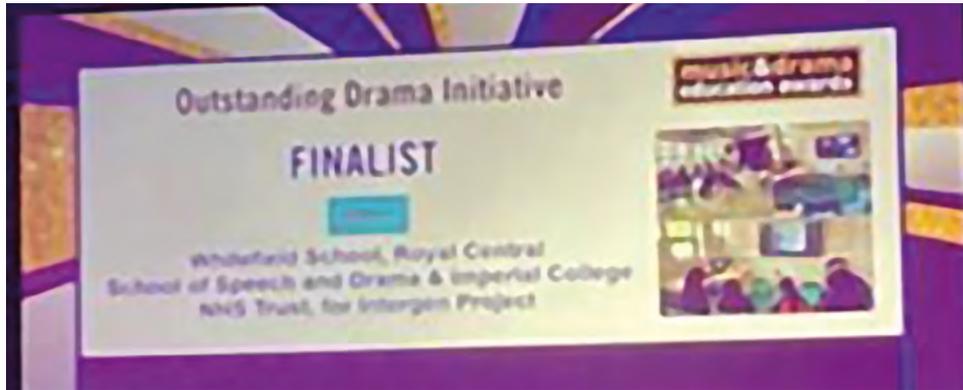


"We had great celebrations in Auchy for the patients' afternoon tea with fizz (non-alcoholic)"
Maura Applebe

"Our patients were so pleased, we all had a lovely tea"
Northwick Park Hospital



Celebrating as Finalists in The Music and Drama Education Awards 2022! – by Maura Applebe



The Auchy Acute Haemodialysis Unit is based at Imperial College Renal and Transplant Centre at Hammersmith Hospital, London

We provide haemodialysis for patients in kidney failure. The unit has 23 haemodialysis stations in an open plan environment with 2 side-rooms. Its busy, very bright and at times noisy!

Most of our haemodialysis outpatients have complex needs that require more nurse and medical interaction than our regular haemodialysis patients. Patients may be post-operative, recovering from stroke, have additional comorbidities and increasingly have progressive dementia, particularly vascular dementia.

The dialysis treatment takes about four hours and requires the patient to lie in a bed. This can be very boring especially for those with visual or hearing impairments.

The Intergen Project was an exciting opportunity to link two groups in society who would otherwise never engage. Patients isolated on dialysis in hospital and Yr 9 students studying drama at school. I was not sure

how the two groups would manage to communicate and collaborate to generate material for performances. This concern was soon eradicated. The facilitators (Rachel, Nicola) used iPads to link the two groups over Teams in a



Collaboration with Dementia Team, Patients and staff from the Auchy Acute Dialysis Unit, Yr9 Whitefield school, Royal Central school of Speech and drama- Nicola Abraham, Rachel Hudspith.

creative dialogue. They bounced ideas off each-other and came up with inspiring and creative ideas for character and plots. Both groups were from diverse backgrounds with the majority of patients being over 65yrs.

In the midst of the pandemic when patients were very fearful of attending hospital. It was wonderful then to hear the project in action and the laughter and giggling of patients while I walked around the unit. Patients chatting with teenagers in an animated and energetic manner.

During the pandemic most of these patients only left their homes to go to dialysis appointments and greatly missed the social interaction of family and friends. Patients who do not have active

engagement on dialysis generally fall asleep and this can disturb their natural sleep pattern. There is also research to suggest that day-time napping is associated with progressive dementia which is very common in our elderly dialysis population.

Patients reported recalling the events of the project to their family and enjoying having something new to talk about and having a general increased sense of self-worth. They felt that they had a life-time of knowledge and wisdom to share and were delighted to have for an opportunity to do this. They also felt they were learning new relevant words and phrases from a different generation and that there was a "coolness" to this! Using the format of Teams was new for all of them and they were very interested in how to develop this in their own lives. Patients said they looked forward to the meetings and that it took away that feeling of having "wasted time" on dialysis and replacing it with "time well spent" instead.

This is a project that I feel could be replicated in other dialysis units to promote intergenerational collaboration and improving patients wellbeing.

Dialysis service – meeting the challenges this winter – by Helen Watts

The winter months brought many challenges to the Dialysis service, but the teams kept calm and carried on with a strong spirit and determination to continue to provide the best care possible for those receiving haemodialysis or peritoneal dialysis treatments in West London.

Covid really challenged us all, where at the peak we had 105 patients dialysing in isolation at the Charing Cross unit at any one time. The Charing Cross team have constantly risen to this challenge as their service changed on a daily basis. This was supported by an incredible administration team and transport service constantly reconfiguring to meet the needs of those afflicted by Covid. The patients with Covid, where indicated were administered with new special treatments to help improve their antibody response and we saw very few patients become seriously ill. The team were amongst the first in the country to give these new treatments of which we are very proud, led by Rachna Bedi our incredible Pharmacy lead. The vaccination programme has also had a significant impact to keep people safe both for staff and patients alike. We sadly did bid a final farewell to a very small number of people and this continues to fill

all of our hearts with sadness. The research led by Michelle Willcombe continues to inform us and help us understand how to manage Covid.

Along the way some great things were achieved

- Auchi team became finalists in the music and drama education awards where they collaborated with the Dementia team on the Intergen Project. This was an exciting opportunity to link two groups in society who would otherwise never engage -Patients isolated on dialysis in hospital and Yr9 Drama students from Whitefield secondary school. They collaborated remotely on Teams to develop a drama including plot, characters and dialogue which was then produced by the students.
- The home therapies team won a Trust Team excellence award for their work supporting those new to Dialysis in commencing Dialysis at home.

- Aumeshree Alwar, unit manager in Auchi researched nurse experience in caring for patients on Dialysis with mental health conditions and won the Imperial College 'peoples' choice award' for a poster and published her work in the Renal Journal of Nursing
- Edric Tsai, staff nurse Auchi wrote an article 'my story as a haemodialysis nurse' on the Filipino website to inspire Filipino nurses to look to a career in renal nursing.
- Health care support workers have been supported to complete their nurse training via an apprenticeship route and we congratulated Karen Vasquez at Ealing, with three more in training.

We said some goodbyes to 3 satellite Head nurses, Sharon Harris, Virginia Prout and Kathleen Lynch as they retired and also to ward managers Mary Lesabe and Debbie Haynes. These nurses had approximately 180 years of experience between them. We thank them for their kind, caring dedication and wish them much happiness as they enter their new chapters in life. These departures brought us new leadership for the future where Cherry Manilay (Hayes) and Merlin Peter (Watford)

were promoted to head Nurses and we welcomed Annah Karanja as the new Head nurse at St Charles. We also saw the promotion of Anandini Khumanthem (Auchi), Mylene Rebenque (Brent) and April Arribas (Northwick Park). We wish all these nurses a wonderful future in the Dialysis service as they carry on with the legacies left by their predecessors. We have also welcomed approximately 25 new nurses from the Philippines to our team as we progress with international recruitment.

This last week we have had the joy of celebrating the Platinum Jubilee with the support of the WLKPA who kindly funded the areas so that the flags and balloons could go up, and a few treats could be shared to mark this momentous occasion. The photographs say it all as to what a wonderful Dialysis family we have at Imperial.

There is always much more to achieve though and we look now to the publication of the 2021 Patient reported experience measures (PREM) by the UK Kidney Association. From this we hope to learn from you in order to keep growing together and provide the best service that we possibly can.

Renal Counselling & Social Support Team by – Beverley Mealor

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

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

We thought it may be of interest that we had an article on the BACP (British Association for Counselling & Psychotherapy) website in March for World Kidney day. This article discusses the need for increased access to counselling support for kidney patients.

You can access the article from the following link; <https://rb.gy/0f6plu>

“This article first appeared on the website of the British Association for Counselling and Psychotherapy (BACP)”

The last year has been one of considerable financial strain for many people and the continued increase to food and energy prices continues to impact daily life.

Kidney Care UK provide grants to dialysis patients and families on a low income as well as some transplant patients, and if your health and quality of life is being seriously affected by your renal condition. Grants can be towards domestic bills,

household items, or holidays. Find out more at; <https://rb.gy/m6qin9>

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.

Many mobile phone providers are offering sim only deals that are considerably cheaper than a standard contract. Vodafone are offering a “Voxi for now” deal for people who receive some government benefits. For £10 month you can get endless data, calls and texts for 6 months with the flexibility to cancel, pause or change at anytime. Find out more at www.voxi.co.uk. Giff Gaff offer a monthly recurring, unlimited minutes and texts with 15GB of data for £10/month and Virgin offer a 12 month contract for £7/ month which includes unlimited calls and texts with 10GB of data.

Broadband social tariffs are not widely advertised but can save you a lot on broadband costs. To qualify you need to be receiving certain government benefits. Jobseekers on Universal credit who don't have an internet connection can check their eligibility for 6 months free TalkTalk connection. Eligibility is determined via jobcentre staff.

Other companies offering a social tariff are BT Home essentials broadband and line for £15/ month for average 36MB speed. You can find out more here: <https://rb.gy/omzwob>

Are you paying for prescriptions and health costs? Check whether you are eligible for a medical or financial exemption if you are receiving benefits or are on a low income. Who can get free prescriptions - www.nhs.uk/nhs-services/prescriptions-and-pharmacies/who-can-get-free-prescriptions. Alternatively, you can buy a prescription prepayment certificate for £30.25 for 3 months or £108.10 for 1 years' worth of prescriptions. Get a prescription prepayment certificate - www.gov.uk/get-a-ppc

If you receive disability benefits, work related benefits or carers allowance, you may be able to access free leisure membership

with your local council run leisure centre. Contact your local leisure centre to find out more.

Kidney beam is an online exercise programme that is currently free that offers live and on demand exercises, pilates and yoga that are specifically designed for renal patients. Find out more at beamfeelgood.com/kidney-disease

Regular meditation can make a significant difference to your mental wellbeing. There are also a number of meditation apps such as Liberate – a mediation app for and by the black community Liberate - Daily meditation app for the Black experience (liberatemeditation.com) and Headspace - which provides tools and resources to help reduce stress, improve resilience and aid better sleep www.headspace.com. The NHS also has a number of apps which can help with mental wellbeing. [NHS-Mental-Health-Apps.pdf](https://www.nhs.uk/mental-health-apps/) (bsuh.nhs.uk)

Apps such as Too Good to Go lets you buy food at the end of the day from hundreds of shops and restaurants and supermarkets at a reduced price.

Finally – if you are in debt, get specialised help. You can contact Stepchange Debt Charity for free expert advice and fee-free debt management. You can contact them on 0800 138 1111 or via their website. www.stepchange.org.

Superfoods – Can they help my kidneys?

by – Costanza Stocchi

In the last few years, there has been a large wave of “superfoods” advertised on the internet and social media. This article explores some common so-called superfoods.

Our kidneys are the body’s filters and work hard every day to flush water and toxins out. When they are not working well, it might be tempting to turn to herbal remedies and superfoods to help make them work better. However, food is not medicine, and these superfoods will not help improve your kidney function - they might even increase the stress on the kidneys!

Chia seeds:

Chia seeds’ boom as a superfood is not new. These very tiny seeds can now be found in cereal bars, granola and even in bread – and for good reason. They are high in omega-3 fats, which are anti-inflammatory and good for your heart. Like all seeds and nuts, chia seeds are particularly high in potassium and phosphate. If you are on a potassium restriction, having a lot might be harmful.

Turmeric:

Turmeric is one of the main ingredients in store-bought curry powder, and a tasty addition to dahls, sauces, cakes or even coffee.



The bright yellow powder (or root) is very high in curcumin – another nutrient reported to have anti-inflammatory properties. While it can be great to add a pinch to add flavour and colour to soups and curries, turmeric is high in potassium, so not ideal to load up on if you are trying to keep your potassium levels down. You can also find turmeric-loaded tablets in some pharmacies, but it is safer to avoid these as the high dose of curcumin could interact with your medications.

Seaweed:

Seaweed has also been gaining popularity in the past few years. Some specific types of seaweed, like spirulina, chlorella or Irish seamoss can be packed full of protein and healthy fats. While a

bit of seaweed wrapped around sushi is fine to eat, the very potent powdered version can do more harm than good if you have kidney disease, as seaweed can be very high in sodium and potassium. Some specific types of seaweed, like chlorella, can even cause damage to a healthy kidney if eaten in high amounts!

So what can I do to stay healthy?

Superfoods sound appealing because they are quick, easy and, for the most part, readily available. However, there is no quick fix or magic pill that can replace a healthy diet. In most cases, a very concentrated extract of things that are good for you ends up doing more harm than good. Remember – there is a lot of marketing behind all these super-foods but not a lot of evidence to say that they work!

Our advice is always to stick to a healthy, balanced diet and fill your plate with a variety of fruit and vegetables, meat or pulses, rice, pasta or bread. If you want to discuss this in more depth, or if you have any questions about your diet so far, feel free to chat to your renal dietitian.



KIDNEY PATIENTS' COVID-19 VACCINATION GUIDE

(ADULTS AND CHILDREN OVER 12 YEARS)



Vaccination	Who			When	How (England) See below for devolved nations
	Chronic Kidney Disease (CKD) stages 1-5	Dialysis patients	Transplant patients/people who are severely immunosuppressed		
1st primary dose	✓	✓	✓	ASAP	<ul style="list-style-type: none"> Book online Walk in vaccination site
2nd primary dose	✓	✓	✓	From 8 weeks after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site Under 18s need to take proof of eligibility if less than 12 weeks from previous dose, or contact GP surgery
3rd primary dose	✗	✗	✓	From 8 weeks after previous dose	<ul style="list-style-type: none"> Book online Walk in vaccination site with proof of eligibility
1st booster	✓	✓	✓	From 3 months after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site (with proof of eligibility if "4th dose")
Spring booster	✗	✗	✓	From 3-6 months after previous dose	<ul style="list-style-type: none"> Book online Walk-in vaccination site with proof of eligibility
Autumn booster (2022)	TBC	TBC	TBC	TBC	TBC

Being fully vaccinated can reduce your risk of becoming seriously ill, hospitalisation or death from Covid-19

SPRING BOOSTER:

As per the [Green Book](#), the preference is for vaccination at around 6 months to maximise its effectiveness, but people who are immunosuppressed can choose to receive it earlier, providing it's at least 3 months from your previous dose.

NHS guidance states that if you book an appointment or go to a walk-in clinic, you should not be turned away, if eligible.

Note: If you have your 4th dose (1st booster) after the end of March, this will count as your spring booster - you will then receive your 5th dose (2nd booster) in the autumn.

For further information on eligibility and timing of the spring booster, see the [Green Book](#), p28.

Examples of proof of eligibility include:

- a letter from your GP or specialist describing your condition or treatment, or inviting you to get vaccinated.
- a prescription or a medicine box with your name and the date on - this must show that you had a severely weakened immune system at the time of your 1st or 2nd dose.

To book a Covid-19 vaccination or for more information

- England
- Scotland - vaccine eligibility tool, or call the National Vaccination Helpline 0800 030 8013
- Wales
- Northern Ireland

PROTECT YOURSELF • STAY CAUTIOUS • SEEK ADVICE



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FILL IN THIS SUDOKU PUZZLE

Each 3x3 box must contain numbers 1-9

The same number must not appear in the same row or column of the 9x9 grid.

Some boxes have been filled in to help you

Answer on the website

www.westlondonkpa.org/newsletters2022

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
Or visit www.westlondonkpa.org**

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26th August 2022

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