Kidney patient Covid-19 update



SEPTEMBER 2020







Uned Ymchwil Arennol Cymru Wales Kidney Research Unit



Welcome to the latest edition of your kidney patient newsletter. We hope this update finds you well.

The theme for this issue is looking after your wellbeing and includes articles on how to keep your mind and body active.

Previous editions are also available online www.kidneyresearchunit.wales/news.htm?id=94

Enjoy this edition!

Exercise at home for free



thanks to Kidney Research UK. Sign up at www.beamfeelgood.com/kidney-disease

MOVE Project has a range of online videos to help people exercise safely at home or during dialysis along with a guide on how to set goals and track progress. Their Get Active Guide includes suggestions of small changes that can lead to a more active lifestyle, such as walking around the house while on the phone, or using stairs instead of a lift when able. You can access the resources at

http://move.bangor.ac.uk/index.php.en

YouTube is a great source of exercise material, most people will have heard of Joe Wicks and his PE classes over the last few months, but there are thousands of different exercise coaches providing free workouts. Simply search for whatever takes your fancy such as pilates, yoga, or cardio and you will find videos for all abilities.

Paul Popham Fund Walk for Health walks are a great way to meet new people and get more active. Each walk is a gentle 1 mile stroll, where walkers can go at their own pace. Designed with kidney patients in mind, each walk member is supported to walk as far and as fast as they are able. All walkers, current and new, are very welcome to join us.

Don't forget to talk to your renal physiotherapist or renal team before taking on any new exercise programmes.



Gyms and leisure centres reopened in Wales on 10th August, much to the delight of gymgoers.

Not everyone is comfortable visiting a gym though, this could be due to recently shielding, anxiety or limited mobility. We all know that exercise is good for your physical health, but did you know it is also a great way to look after your mental health and get a good night's sleep? There is no 'one size fits all' approach to exercise, so we have listed a number of ways you can exercise without an expensive gym membership.

Kidney Beam is a website that offers a selection of pre-recorded exercise videos, along with live sessions you can join throughout the week. From seated exercises to high intensity interval training (HIIT) it caters to people of all abilities. Beam is usually a subscription service, but all members of the kidney community are able to make the most of a free membership until 30th November

Going Digital

Many of you will have noticed the arrival of iPod touches at your unit in the last week, or even joined in the virtual conference using one.

We have secured these devices from Phones for Patients so that we can make our work more accessible to those who may not have access to online resources while on dialysis.

These devices are designated for joining virtual conferences, completing surveys such as PREMs and accessing patient information from the NHS and renal charities. Each device will come with an easy guide on how to use, so there's no need to worry if you've not used one before.

If you have used one of the new iPod touches we would love to hear your feedback.

British Transplant Games

Last summer the British Transplant Games were held in Newport and saw thousands of transplanted athletes and supporters come together to celebrate and raise awareness of organ donation.

Sadly this year's games couldn't take place in Coventry, but we were able to get together virtually and share our socially distant sports.

If you've been inspired to take part in next year's games in Leeds or would like more information please contact Shaun Thomas on 07866 810401.



Tim from North Wales says:

"I'd had my transplant in October 2014 and I was keen to get active once again so the games were a good focus for me as I'd began to run a bit to aid my recovery from the operation.

I found the transplant games were great to experience in a friendly competitive atmosphere. There are variety of sports on offer. You could do all sorts from cricket, fishing and snooker to cycling, swimming and track and field, it catered for all abilities. Some like to be serious, others not so much. For me it was more about taking part and the positive experience. On a personal level it was really important for me to represent my sister and show my thanks to her for donating her kidney to me.

If you'd like something to focus on and keep healthy physically and mentally I'd recommend anyone to join their transplant team and try the games at least once. You will feel inspired by your transplant community and what you can achieve too."



Meet your MDT

In issue 7 we introduced you to some members of the Multi-Disciplinary Team that work alongside your doctors and nurses to look after your kidney health and social care needs.

In this issue we would like to introduce you to some of the people who are here to look after your physical fitness and diet.



Occupational Therapist
Hello, my name is
Matthew Shepperd and I
am a rotational Occupational
Therapist working on a
specialist renal ward at
Morriston Hospital. I

collaborate and work in a multidisciplinary team to ensure patient's needs and wishes are addressed throughout the stages of chronic kidney disease. The aim of my role is to enhance patient's quality of life with a focus on increasing skills to maintain or increase their independence and facilitate safe discharge through assessment for and provision of appropriate equipment. My reflections are that throughout the pandemic all members of the MDT have worked seamlessly to ensure the needs and wishes of the patients are met in an empathetic manner on the wards with emphasis placed on safe discharges to minimise risk of infection of Covid-19.



Physiotherapist

Hi, I'm **Lou Kennedy** and I am the Specialist Physiotherapist in Nephrology and Transplant at UHW. I have been working here for almost 10

years and in the renal speciality for over 13. I work with patients on wards B5 and the Cardiff Transplant Unit to rehabilitate them after illness or surgery. We have an amazing proactive multidisciplinary team who are all dedicated to the Get up, Get Dressed, Get Moving campaign which has seen our patients rehabilitate and go home with the support they need more promptly every year.

Another of my roles is in the BALANCE Lifestyle Management programme which is an outpatient based service aiming to help participants who have received, or due to have, a transplant, those who have, or are going to donate a kidney, and those who are making decisions on renal replacement therapy. It is run by a specialist physiotherapist and dietitian and combines diet and lifestyle advice with a circuit style exercise class. Last year I accepted the position of Chair of the British Renal Society Rehabilitation Network.

The Network promotes research and multidisciplinary collaboration into rehabilitation of patients with renal disease. I love my job and the opportunity to educate on all things kidney and rehab related and my next project is to promote exercise on dialysis at our dialysis units.



Renal Dietician

Laura and Sarah are renal dietitians based in Wrexham. We try to be friendly and approachable and aim to work with each of you, providing information and guidance so you can enjoy a healthy renal diet. We provide dietetic care to inpatients and support home therapy patients dialysing in the community as well as those not requiring dialysis. We are getting used to new ways of working and are phoning patients instead of clinic appointments, but when we do visit the renal units we ensure we comply with all COVID personal protective guidance.

During the COVID crisis we have focused on helping those self-isolating to improve their access to food and additional help, we have provided specialist information on fluid and potassium management, to help to keep people safe. We support individuals who are struggling with their appetite, perhaps after a COVID infection, to boost their intake and keep them healthy and regain their strength and independence. In the future we are hoping to offer video consultations as an alternative to clinic appointments or phone call. We are contactable via phone or email for any queries you may have and we have managed to maintain a full service throughout the crisis and work with the rest of the team to support you in these challenging times.

Virtual Kidney Patient Conference

Kidney Care UK, Kidney Wales and The Paul Popham Fund held a virtual conference on Wednesday 2nd September, providing advice and guidance to kidney patients in light of the Covid-19 pandemic.

Guest speakers included Fiona Loud, Kidney Care UK Director of Policy and Mike Stephens, Consultant Transplant Surgeon at University Hospital of Wales. If you were unable to join the conference a recording and summary of key points is available at http://kidneypatientconference.wales/



Flu Vaccines

It's that time of year again where we are preparing for the winter months which means that flu season is around the corner. Having the flu vaccine is the best

CURWCH FFLIW BEAT FLU

way to protect yourself, family members and the wider NHS and social care system from the strains of flu Flu presents a significant risk to those with chronic kidney disease. Having the flu can:

- Kill
- Cause severe worsening in your other longterm health conditions
- Require an admission to hospital

Affect people with kidney transplants or those on the kidney transplant waiting list.

Get your flu vaccine from your GP Surgery, Community pharmacy, Dialysis Unit (for those on unit haemodialysis).

For more information visit www.beatflu.org or speak to a health care professional.

Prescribing Goes Digital

Everyone is going digital and the good news is - so is your dialysis unit!

You will notice in the coming months positive changes on how your medicines will be prescribed and administered. This is called the Electronic Prescribing and Medicines Administration or EPMA. This is a digital system being introduced to all dialysis units in Wales and has been implemented successfully in South West Wales. The great thing about EPMA is that it will allow your dialysis nurse to spend more time with you during your dialysis and less time on the paper work - in fact there will is no paperwork!



One of the first changes you will notice in your dialysis unit are mobile carts and a small group of new faces. This friendly group of people will include renal pharmacists, renal nurses and renal IT engineers, they will provide training to your dialysis team on how to use the EPMA system. The nifty little mobile carts will allow staff to access your EPMA and dialysis records and also keep a small supply of your dialysis medicines.

The biggest benefit of all is to you! At a touch of a button on either your smartphone or home computer you will have instant access to your dialysis medicines and blood test results. The EPMA system will keep you up to date and fully informed about your kidney disease and treatment.

The New Normal

Now that shielding has been paused, many people will be venturing to public places and seeing crowds for the first time since March.

This can be guite daunting for someone who has spent the last six months with little interaction outside of their home or dialysis unit and it's natural to experience anxiety the first time they visit a supermarket or café and notice changes. There are a number of ways you can maintain social distancing while out and about and continue lowering your risk of contracting coronavirus.

Distance Aware Badges



Distance Aware badges are recognised all over the country with many employers and businesses training staff to look out for them and respect the wishes of those wanting to maintain a safe distance of 2 metres.

The instantly recognisable vellow shield is now available on badges and lanyards and can be collected from your renal unit or ordered from any of our charities. If you would like extra badges for your household they can be ordered free from



https://www.charitycardshop.com/kidneycareuk/ product/43

Face masks

Face coverings have been compulsory on all public transport in Wales since 27th July.

This applies to buses, trains, coaches, aircraft and taxis. It is good practice to also wear a face covering in situations where social distancing is not possible, however this isn't mandatory. The World Health Organisation recommends that face coverings should consist of three layers which cover the mouth and nose. Always wash your hands before and after applying/removing your

face mask and avoid touching anywhere other than



It's a good idea to have more than one reusable face mask so you can wash them after each use. Medical masks are for a single short

use only, please do not keep and reuse medical masks as they will not be

effective after the first use.

Kidney patients can order a reusable mask free of charge from Kidney Wales

https://www.kidneywales.cymru/news/2020/06/ 10/face-coverings-kidney-patients/

Food shopping

The Welsh Government food box scheme ended on 16th August, but priority supermarket delivery slots remain in place.

If you have not signed up for a priority slot yet, you are still able to so long as you use the same name and address from your initial shielding letter received from the Chief Medical Officer. Many supermarkets are also selling food boxes of essential items, but bear in mind that these boxes will not necessarily cater for a kidney diet. Local councils and community groups will continue to offer support with food shopping or prescription collection for those that have been shielding.

Hospitality

Cafés, bars and restaurants are now open indoors and outdoors in Wales with social distancing in place.

Most venues are operating a booking system to avoid overcrowding and will be taking contact details of each visitor to ensure that the Test, Trace, Protect approach can be carried out in the event of any visitors developing symptoms. You will find hand sanitising stations at the entrance and counters of most venues, while tables and chairs are thoroughly cleaned between each

Meeting others

It can be very tempting to fall back into old habits now shielding has paused, but it's important to still maintain social distancing while meeting with friends and family outside of your household bubble.

Great ways to connect with others away from a screen would be a socially distant picnic or a catch-up in the gardens we've all been working on through the shielding period.

Summary of current restrictions

- Certain businesses are not allowed to open
- People should not gather indoors with anyone who is not a member of their household (or extended household) unless they have good reason
- Social distancing of at least 2 metres should be maintained in public
- People must not gather outdoors in groups of more than 30

Your outdoor checklist:

- Distance aware badge or lanyard
- Face covering (keep in a sealed bag rather than loose in handbag or pockets)
- Hand sanitiser
- Sanitiser wipes

Kidney Wales recently held an online Q&A **Gerhand**, who shared practical exercises and tips on managing stress and anxiety coming out of shielding. These can be viewed at

https://www.kidneywales.cymru/news/2 020/08/10/9072/

What are the risks of catching COVID-19 from various activities?

Your level of risk will go up and down with the level of infection in your community.

This document is only a guide and you should use it to support you in having conversations about your personal risk level with your own healthcare professionals.

Patient story

Jamie Bowen

2020 has been a strange year. I have been classed as extremely vulnerable and told to stay within the 4 walls of my home for almost 6 months of the year.

So how was someone who is fit and healthy and loves mountain walking and biking going to cope? The answer was to recreate mountains via my own staircase with a fully loaded rucksack.

I was able to calculate how many steps it would take me to climb some of the biggest mountains in Wales; 433 for Snowdon by the way. Yes it was boring but knowing that being fit and active gives you a better chance of fighting COVID-19, you have to try. Besides, exercise gives you the happy endorphins that you need during shielding.

Mentally it was really tough and the only escape I had from 2020 to a more normal life was through books. Early on concentration suffered but I came



through and I've been able to go back in time, journey through space, fight crime, travel over to New York, up to Cumbria and all over Scotland! So many places to see when I really had nowhere to go. Reading has helped me so much and I've now read nearly 100 books for the year!

We've had to adapt in so many ways, but hopefully it's taught us a lot about ourselves and what is really important in life.

Did you know?

Many car insurers are offering a discount if you've been driving less than your expected mileage during the

Your insurer will contact you to let you know if you're eligible, it only takes two minutes and could result in a nice surprise! For more tips on how to maximise your income, visit https://www.kidneycareuk.org/newsandcampaigns/news/income-maximisation/

Supporting young adults with kidney disease

The move from paediatrics to adult services continues to be a challenging and turbulent time for some of our younger patients, despite much attention and effort being made to support young patients with this move in recent times.



It is very common for patients and their families to be worried about the move across to adult services. But, in reality people need not have these fears. We just need to help these families prepare for the move and have the opportunity to discuss their concerns! We find that when we get these things right, people flourish and do really well when they move across.

One thing we try to encourage is patients starting to see healthcare staff on their own (for parts of

their appointment at least). This is important as young people get to the age where they may want more independence or to discuss personal issue. Also, it is intended to prepare them for adult life when they may not always have a family member to attend with them. We want young patients to feel confident talking about their condition, being open about how they're feeling, understanding their treatments, medications and the options available.

Every year our younger patients go on a residential trip to West Wales, organised by the Renal Youth Worker, where they can take part in a wide range of activities build their self-confidence. This year's trip had to be cancelled due to the pandemic, but we have plans for 2021 to run a trip again to West Wales.

If you know any young people who would like to get involved please get in touch on 07866810401 or Shaun.Thomas2@wales.nhs.uk



Patient story

The Paul Popham Fund, Walk for Health Groups walk leader was told to shield during the Pandemic!

Late March came the decision for Geraint John to isolate and leave work, which subsequently led very quickly to furlough. Isolate? Up to that point Geraint had been walking nearly every day, since having his transplant in ???? he in fact took on the challenge of trekking to Base Camp Everest in 2018 for the charity. Just like all who were told to shield this was a shock to Geraint. This is what he did to combat isolation, lack of walking to keep himself motivated and positive during that time.

"I started the garden, digging, hammering, levelling, perspiring, (probably swearing) putting in wooden steps between the top and bottom level. Dug out steps, repaired walls, etc. I asked myself - how can I turn this situation into a positive - I am a walker and when I was told to shield that was the first thing I thought, I can't work or walk what will I do? I soon found the solution of walking in the garden, gardening and a charity walk around the garden to raise money for the charity."

And that is exactly what Geraint did he turned his love of walking to raise money for the Paul Popham Fund during this time. Walking 50,000 steps around his newly developed garden and raised £2000 which was ring fenced to buy just under 20 magnifying lamps for the home therapies department at Morriston Hospital and afternoon tea for over 400 patients and staff at Liz Baker and the Renal West Dialysis Units at Morriston Hospital!

PPF Careline

The PPF Careline is manned by volunteers and staff of the Paul Popham Fund, all of which have kidney disease or are a family member of a person with kidney disease. They

empaphise with you and are ready to answer your question. There is no need to feel lonely or isolated you can pick up the phone between 9am and 6pm Monday to Friday and talk to someone who understands. Outside these hours you can arrange for someone to call you.

Call the Careline on **0800 038 8989** or email **support@paulpophamfund.co.uk** to let us have some details and to set up a password to use at the start of every call. This is to give you peace of mind so you know you're speaking to a Paul Popham Fund Peer Mentor.

Pick up the phone for a chat with someone who cares!



Recipe of the week!

Kidney Care UK continue to develop new recipes as part of the Kidney Kitchen initiative. All recipes are created with a renal diet in mind providing nutritional information and tips on how to adapt to specific dietary requirements. This week we are featuring these delicious fishcakes.

Leek, parsley and chive fishcakes:

INGREDIENTS

- 3 medium potatoes
- 100g salmon, skinless and boneless
- 100g pollock, skinless and boneless
- Zest of one small lemon
- 1 tablespoon fresh parsley
- 1 tablespoon fresh chives

- 1 leel
- Freshly ground black pepper
- 2 eggs, beaten
- 4oz plain flour
- 6oz fresh white or panko breadcrumbs
- 3 tablespoons vegetable oil
- 80g mixed salad leaves



K dney K tchen

Visit www.kidneykitchen.org for the step-by-step method and to see more tasty recipes.

For information & support

Team from Kidney Care UK Head Office: 01420 541424

Wales Advocacy Officer: 01656 514776
E: Linzi.lsaac@kidneycareuk.org

Team from Kidney Wales

T: 02920 343940

E: team@kidneywales.cymru

Team from Paul Popham Fund

T: 01792 654182

E: enquiries@paulpophamfund.co.uk