

# Kidney patient Covid-19 update



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Uned Ymchwil Arennol Cymru  
Wales Kidney Research Unit



Welcome to the tenth issue of this newsletter, where we reflect on the first phase of the pandemic, and as we move into a new national firebreak lockdown, we will look at how to keep safe and well. Happy reading!

## Welsh kidney charities - here to support patients

Kidney Care UK, Kidney Wales and Paul Popham Fund are working closely together to support people with kidney disease by providing information, guidance, emotional support and grants to help patients in need of urgent financial assistance.

Throughout the pandemic, together we have answered 469 enquiries from patients and families and given £24,752 to 79 patients, families and carers in need of urgent financial assistance.

Here are some of the other things we have done to support patients during the pandemic.



### Post-Transplant Kidney Café

This is a Support group for transplant patients. During this unprecedented time you can access the support group on-line and join virtual group meetings. To join the group and virtual meetings where you can gain support from your peers in a confidential and private space, type the address into your internet browser, or go to facebook, search 'South Wales Kidney Transplant Café' and request access.

Friends and family welcome

To find out more please visit the on-line support group or call: **0800 038 8989** Email: [support@paulpophamfund.co.uk](mailto:support@paulpophamfund.co.uk)  
<https://www.facebook.com/groups/SouthWalesKidneyTransplant>

Call us: **0333 2001 285** [www.paulpophamfund.co.uk](http://www.paulpophamfund.co.uk) [www.paulpophamfund.co.uk](http://www.paulpophamfund.co.uk)  
enquiries@paulpophamfund.co.uk

Paul Popham Fund  
Kidney Café



### Q&A with Dr Mike Stephens

Consultant Transplant Surgeon

Tuesday 9 June at 7pm  
Kidney Wales Community Facebook Group

Email questions by 9am  
Monday 8 June to  
[judith@kidneywales.cymru](mailto:judith@kidneywales.cymru)



Paul Popham Fund Befriending Service  
Putting Kidney Patients First

Paul Popham Fund Befrienders



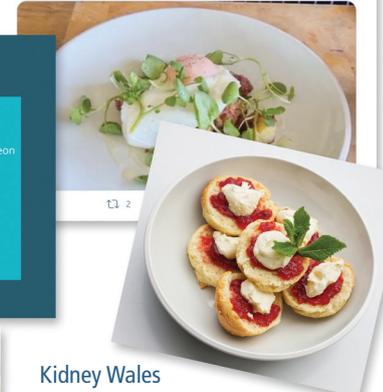
### Coronavirus (Covid-19) guidance for patients with...

NHS recommends people with chronic conditions follow strict distancing

Read more

Kidney Care UK  
Coronavirus  
Guidance

Kidney Care UK  
Lockdown  
Recipes



Kidney Wales  
Q&A

None of this would have been possible without our fantastic supporters and fundraisers:

**DIOLCH!**



2,000 Face Coverings distributed to our Kidney Community

Diolch/Thanks you

Kidney Wales Face Coverings

## Latest Coronavirus guidance

Guidance from government about how to keep safe during the pandemic is changing rapidly, with a new layer for specific local lockdowns.

It's important to be aware that the rules for the local lockdowns are made by local authorities and are different for every area. Please check the rules that relate specifically to the area you live in - through local news, radio, press and local government websites.

If you are unable to access basic food or medicine supplies, or social care needs, due to local lockdown restrictions, please speak to your healthcare team, Social Worker or kidney charities.

To track the latest information and keep safe, please follow these steps:

1. Keep track of the current guidance! Check the latest guidance published by Welsh Government: <https://gov.wales/coronavirus-firebreak-frequently-asked-questions>
2. In recognition of the emotional toll Coronavirus is having on people living alone, the

First Minister for Wales has announced that adults living alone, including single parents, in areas under local restrictions are able to form a temporary bubble with another household in their local area.

3. Check the latest Coronavirus guidance for people with kidney disease from Kidney Care UK: <https://www.kidneycareuk.org/news-and-campaigns/coronavirus-advice/> Or contact the Welsh kidney charities to have your questions answered.
4. If you are on the transplant waiting list, the Renal Association recommends speaking to your kidney doctor about whether you should continue to shield. If you have had a transplant in the last three months, you should be shielding.
5. Always observe social distancing with those outside of your household - stay 2 metres (3 steps) away from others, indoors and outdoors.

6. Meeting anyone outside of your household (or approved extended household for adults living alone) indoors or outdoors is prohibited during the firebreak. You must not meet up with anyone you do not live with, except in very limited circumstances such as providing or receiving care.
7. Wear your #Distance Aware badge with pride! Politely let people around you know that you'd like a social distance to be respected.
8. Wear a face covering - it is now a requirement on public transport and in shops and other indoor public places.
9. For people who have been shielding, utilise priority shopping slots for supermarkets, shop at quieter times of day or ask family or friends to help you.
10. Wash your hands for 20 seconds with soap and water regularly and use hand sanitiser where hand washing facilities are not available. Avoid touching surfaces that have been touched by others.

# Keeping well this winter

As the days get shorter and the darker evenings set in, here are some tips to help you keep feeling physically well this winter:

## Keep active

Weather permitting, aim to get some fresh air every day, and try to get out for a walk if you feel able.

If you use the internet, there are a wealth of online exercises to try out indoors, including these options which are specifically for people with kidney disease:

- **MOVE Project** for dialysis patients: <http://move.bangor.ac.uk/info-patients.php.en>
- **Kidney Beam** - a resource for people living with kidney disease to feel good through movement, education and well-being support: <https://beamfeelgood.com/kidney-disease>
- **Walk for Health Walking Group** - The Paul Popham Fund

## Walk for Health Group



'Walk for Health' Our Walk Leader, Geraint, is a kidney transplant recipient, and therefore understands the difficulties that may arise when undertaking exercise as a renal patient.

## Eat well

During winter, aim for at least one hot meal every day as well as hot drinks throughout the day.

If you follow a special renal diet, remember to keep in touch with your Dietician for regular monitoring.

Kidney Care UK have launched new recipes as part of the



Kidney Kitchen initiative. These have been specially put together for people to make using store cupboard ingredients during this difficult time. Try this delicious, comforting recipe.

## Quick lamb and leek hotpot:

This is a simple, quick to make dish that's high in protein and low in potassium and phosphate. Perfect for a post dialysis dinner.

If you'd like to join us, or for more information, please contact Geraint on 07774 619 473 or call the Careline on 0800 038 8989

## Keep warm

Try not to sit still for more than one hour at a time. Even if you just move your arms and legs, it'll help you keep warm.

You may be able to claim financial and practical help with heating your home. Grants available include the Winter Fuel Payment and the Cold Weather Payment. These payments are automatically provided to all that are eligible.

Kidney Care UK, Kidney Wales and The Paul Popham Fund all provide grants to patients who are facing financial hardship. The charities can provide financial support if you are finding it difficult to keep your home warm over winter, whether you are on a pre-payment meter or pay quarterly, we encourage you to get in touch.

## Have you had your flu vaccine this year?

Flu (also known as influenza) can be serious and having a flu vaccination every year is the best way to protect yourself.

If you have been shielding, you may be at high risk of being very unwell if you catch flu, but there is a safe and free vaccine for you and your household contacts.

Protect yourself and others, get your flu vaccine at your GP surgery or community pharmacy ASAP.

[www.beatflu.org](http://www.beatflu.org)



### INGREDIENTS

- 400g white potatoes
- 1 large leek
- 500g diced lamb leg steak
- 1 tablespoon oil
- 2 sprigs of fresh rosemary chopped
- 500ml low salt lamb gravy
- 160g green beans
- 1 tablespoon butter
- Black pepper

Prep time: 10 mins

Cook: 30 mins

Serves: 4

Visit the link below on Kidney Care UK for the method and more delicious recipes.

[www.kidneykitchen.org](http://www.kidneykitchen.org)

# Home haemo dialysis

Mair, a new home haemo dialysis patient from, Conwy, talks about her recent experience:



*It all started back in February 2019 when I was diagnosed with multi myeloma. The cancer attacked my kidneys which meant I required dialysis. When I was told I was going to need dialysis on a regular basis for the rest of my life, to say it came as a shock is putting it mildly. It was like being hit by a train, for the second time!*

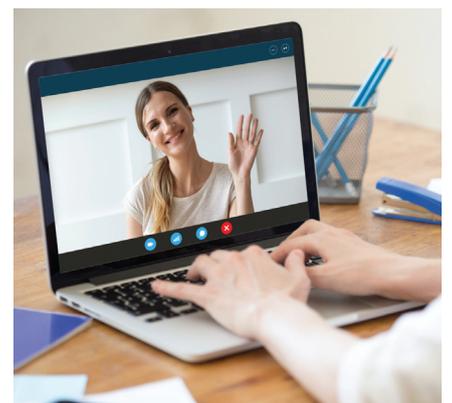
*At the beginning I was very sceptical and it all seemed like too much hassle and upheaval. Where would I put all the equipment? How would we sort out the training? How much would it cost us? I soon discovered that we didn't need that much space and it would all be installed free of charge.*

*Our home dialysis nurse, Melanie, could not have been more supportive and encouraging. She gave me the faith to believe that I could have dialysis in the comfort of my own home, along with all the flexibility that goes with it.*

*I have gone from knowing nothing about dialysis whatsoever to managing my own care. There is no more travelling backwards and forwards to the hospital. I also feel that as Covid unfortunately is not going away, it cuts down the risks of catching it. The benefits definitely outweigh the challenges.*

*I've been fortunate to have been offered the services of the clinical psychologist. This has been invaluable for my sanity, a lifesaver especially with the world being in such a state flux. If you have ever thought about calling on these services, don't hold back, take the bull by the horns and ask.*

*The team couldn't be more supportive and encouraging!*



# We don't know what we don't know about home dialysis!



In Wales, approx. 80% of patients dialyse at a unit, 12.5% have Peritoneal Dialysis at home and 7.5% of patients have home haemo dialysis.

Patients who have home haemo dialysis report the benefits of feeling physically and mentally well, without the need to follow strict dietary restrictions, and with more freedom and flexibility to fit their treatment around their lives.

'Normal' kidneys work 24 hours a day, 7 days a week, 52 weeks a year. It is impossible for a dialysis machine to do the job of 'normal' kidneys in just 12 hours a week!

Hayleigh Isaac, Support Services co-ordinator at the Paul Popham Fund, estimates that over the nine years she has done nocturnal dialysis at home she has had 22,400 treatment hours, versus the 5616 hours that a unit based dialysis patient would have received. As a result Hayleigh feels well, has more energy and more time to spend with family and friends and do the things she loves.

Gail Williams, Lead Nurse for the Welsh Renal Clinical Network, shares her experience and enthusiasm for supporting patients to dialyse at home.

*"We don't know what we don't know about home dialysis. Interesting title don't you think!"*

This came about when listening to a patient sharing his experience in switching to home dialysis after receiving dialysis in a unit for more than three years. He, explained about the excellent training received, allowing himself to 'self manage' confidently at home. But what really shone through was optimism for a better way of life whilst continuing to receive dialysis by just doing it a bit differently!

So based on this, I wanted to make sure that everyone in Wales knows about the benefits of home dialysis. In my former role, as home dialysis nurse, I have witnessed first-hand the benefits that dialysis at home has offered to many

patients and their families; which is pretty amazing I have to say!

The proverb 'don't put all your eggs in one basket' rings true when making decisions around dialysis! I just wished that more people took a leap of faith and in trusting their own abilities. Remember, you don't know what you don't know!

Why not learn about dialysis and give it a go! I would always encourage patients to 'try before you buy' with a reassurance of 'if it's not for you then you have the safety net of the dialysis unit to fall back on'. Nothing to lose either way!

When I chat to patients and their families, I try and explain that 'you will feel better when you do more dialysis, initially this does shock people! But I go on to explain that 'normal' kidneys work 24 hours a day, 7 days a week, 52 weeks a year. It is impossible for a dialysis machine to do the job of 'normal' kidneys in just 12 hours a week; and this is why there are so many restrictions such as appointment times, travel to and from, fluid and diet restrictions etc.

This is where home dialysis comes into its own, flexible treatments; you choose day or night! In Wales, there are 294 people receiving dialysis in the comfort of their own home.

Feel free to ask your teams or kidney charities to put you in touch with people who are self managing their dialysis at home. Find out a bit more! You will be amazed on how confident, competent and safe people receiving home dialysis feel, especially now during the recent pandemic.

Finally, if you live in a one bedroom flat, living alone, have pets, or are just generally worried; speak to your clinical teams, peers and the Paul Popham Fund Peer Mentors.

These are not barriers! If your team agree that you are a suitable, then home dialysis can be easily adapted to meet your circumstances and allow you to live the best life possible."

# Want to find out more?

If you're thinking about home dialysis as a possible treatment option, please speak to your healthcare team and take a look at these resources:

- A film co-produced with people who are on home dialysis: [https://www.youtube.com/channel/UCuMnTURP10rWTuKw9Y\\_eu-A?view\\_as=subscriber](https://www.youtube.com/channel/UCuMnTURP10rWTuKw9Y_eu-A?view_as=subscriber)
- Paul Popham Fund home therapies virtual Q&A: <http://paulpophamfund.co.uk/firsthome-therapies-virtual-qa-explore-and-give-it-a-go/>
- Diary of a Kidney Warrior podcast: <https://diaryofakidneywarrior.podbean.com/>

An all Wales study learning more about the barriers to home dialysis has won the All Wales Health and Care Research Award for Patient and Public involvement - proactively involving patients, families, and professionals throughout the research process to help us work together to design more sustainable kidney health and social care services for people in Wales, all to improve patients overall health and wellbeing, <http://www.researchwalesconference2020.com/awards>

You can read more here, <http://www.kidneyresearchunit.wales/impact-case-studies.htm?id=17> and the exciting thing is that there is lots more to come!

**If you would like to hear more about the research just drop us a line.**



## We're Listening

**CALL Mental Health Listening Line**

Call: **0800 132 737**

**Kidney Care UK Counselling and Support Service**

Call 01420 541424 to book an appointment with a renal counsellor, or contact us via email.

**Paul Popham Fund Careline**

Call the Careline on 0800 038 8989 or email [support@paulpophamfund.co.uk](mailto:support@paulpophamfund.co.uk)

*Don't suffer alone, we are here to help!*

# Lockdown reflections

*"So here we are back in lockdown, the original lockdown seems to be a long time ago, time certainly flies despite the fact that we have nothing to do. A strange environment for us all to be part of and many challenges, but we've managed and learnt a lot. We've got used to online shopping, used to zoom/teams and all the new ways we now communicate and keep that social contact and had to find new and fun ways of keeping fit. The Kidney community has responded well with Kidney Wales, Paul Popham Fund and Kidney Care UK leading the way with the many concerns and questions that patients had and supporting them in new ways also. I was involved in running the virtual book club for Kidney Wales, Renal Readers, it was great fun to provide recommendations for people across different genres, and goodness knows we need to be kept entertained. I've been involved in Q&As with Paul Popham Fund to provide help and support to patients and help them find their way through this new world. I was also called upon to speak to the media about shielding, great excitement at being on the BBC Ten o'clock News.*

*If you're a kidney patient, whether it be your kidneys failing, on dialysis or had a transplant, you've already faced a lot through life, to have COVID-19 on top and find yourself at high risk from it, is a challenge I'm sure we could all have done without. But we've come through it, we've had to find resilience and we're lucky enough to*

*have great charities providing support and championing our cause. The next 6 months could be tough but if we continue to support each other, the happier times will return."*

**Jamie de Lloyd Bowen, transplant patient**

*"Starting a new psychology service in the midst of a pandemic has been an interesting experience...but hugely positive!! Whilst we have been very aware of the challenges facing patients right now, all the adaptations and innovations in ways of working have really helped us to understand the renal world and enabled us to offer virtual appointments wherever possible. This has been a steep learning curve, but has actually allowed greater flexibility in how and where we can work with our patients."*

**Louise and Amy, Clinical Psychologists, University Hospital of Wales**

*"The last 6 months has proved to be an honour and a privilege caring for our dialysis patients. It quickly became an unprecedented and unpredictable journey for us all. As patients shielded from the enemy and gave their trust and faith into the unit staff, it allowed us in turn to truly ensure the very best possible protection for our patients. More than ever the unit proved to be a family community-and this incredible relationship helps us all get through this. I truly give a huge thank you to all the patients that assisted us in this endeavour. The "new normal"*



*is certainly here to stay for a while, but as a close dialysis community-we can and will live with this and beat it."*

**Delyth Timmis, Senior Clinic Manager, Carmarthen Dialysis Unit**

## Kidney Care PREM Survey 2020 - your voice matters!

Kidney Care UK are inviting people with kidney disease to complete the annual PREM - **Patient Reported Experiences Measure** - survey.

The survey data is hugely valued by medical teams and the findings are used to drive improvements in renal services.

By completing the survey, you will be able to report on your own experiences of the care you are receiving, to identify the things that are working well, and highlighting areas for improvement.

For the first time, patients will be asked to complete the survey digitally. The survey is short and only comes around once a year. You are free to answer the survey as honest as you want without being identified.

If you don't have access to the on-line survey because you don't have internet or a device, the dialysis units have access to IPOD touch for you to use for the purpose of accessing the on-line survey, ask your nurses they will be able to help you.

Please complete the survey online before the 12th of November - **Your voice matters!**

See: [https://herts.eu.qualtrics.com/jfe/form/SV\\_b4xiZZpbBAocvS5](https://herts.eu.qualtrics.com/jfe/form/SV_b4xiZZpbBAocvS5)

## For information & support

### Team from Kidney Care UK

Head Office: 01420 541424  
Wales Advocacy Officer: 01656 514776  
E: [Linzi.Isaac@kidneycareuk.org](mailto:Linzi.Isaac@kidneycareuk.org)

### Team from Kidney Wales

T: 02920 343940  
E: [team@kidneywales.cymru](mailto:team@kidneywales.cymru)

### Team from Paul Popham Fund

T: 01792 654182  
E: [enquiries@paulpophamfund.co.uk](mailto:enquiries@paulpophamfund.co.uk)

## Liz Baker Nursing Award winner 2020

Lead nurse Liz Baker passed away in 2017 following a short illness.

Her family set up the Liz Baker Excellence in Renal Nursing Award in collaboration with the Welsh Renal Clinical Network to honour the contribution Liz made to renal nursing in Wales.

The Liz Baker outstanding achievement in nursing award...celebrates a renal nurse in Wales that has gone that extra mile.

This year's winner was **Melanie Hayward**, Home Therapies nurse at Glan Clwyd Hospital.

Melanie said:

*"It is a great honour to the Glan Clwyd team and myself to accept the Liz Baker award and the recognition it gives to renal home therapies, which means so much to me, thank you.*

*Since commencing the home therapies post, St David's day 2019, the support received and the hard work given by the Glan Clwyd Renal unit team has been incredible and helped me in dedicating the best care in supporting patients home safely. BCUHB and national Home therapies teams have also been at hand if I had any questions on starting my journey and I am forever grateful. The external support received by our dialysis providers during this difficult time of Covid has been recognised and I cannot thank them enough in helping us to assist the patient to home haemodialysis safely.*



*The encouragement and education we are able to provide to improve a patient life and the gratitude to be able to dialyse in their own home, has given me a great job satisfaction and has always spurred me on to provide the best care for each individual patient.*

*The last couple of years have not been without its challenges. Whether it be the patients lack of belief in themselves in able to self-dialyse or issues with housing installations. We have adapted elements of the service to be able to accommodate all patient. This is through the introduction of Shared HD and Nocturnal haemodialysis. A home therapies workshop was proven to be a great success in introducing CKD stage 5 patient to dialysis and might be introduced again in the future, if ever safe to do so.*

*Once again, I would like to take this opportunity to thank you for the nomination of this award and the belief in our home therapies service at Glan Clwyd Hospital."*