

# Kidney patient Covid-19 update

ISSUE 2  
MAY 2020



Welcome to the second edition of the **Kidney Patient Newsletter, Covid-19 Update**. Our first edition was based around the guidelines for **Kidney Patients during this time and services available to you**. Edition 2 provides information on what other patients are doing to keep busy and advice on looking after yourself during this time, a general focus on your wellbeing.

As with edition one it has been compiled by Kidney Care UK, Kidney Wales, Paul Popham Fund and the Welsh Renal Clinical Network,

which overseas services for adult kidney patients in Wales.

We hope you find the information useful, we value your opinion and would welcome your feedback on the content, what would you like to see in the newsletter now or in the future please complete and return the evaluations or direct your feedback and general observations to the Kidney Care UK Team on 01420 541424, Kidney Wales Team on 02920 343940 and/or the Paul Popham Fund Team on 01792 654182



## Checklist for staying at home

- **Food:** do you have a way to get food delivered if you need to self isolate?
- **Cleaning:** do you have cleaning supplies?
- **Work:** can you carry on working from home? If not, can you find out your rights to payment or benefits?
- **Medication:** do you have enough medication, or a way to get more?
- **Health:** how to reorganise any planned therapy or treatments?
- **Connectivity:** have you got ways to keep in contact with people you see regularly, like their phone numbers, email addresses? Do you need help setting up digital communication, like a video calling app?
- **Routine:** can you create a routine or timetable for yourself? And if you live with other people, should you create a household schedule? Do you need to agree how the household will run with everyone at home all day?
- **Exercise:** is there any physical activity you can do inside your home, like going up and down the stairs, using bean tins as weights, or exercises you can do in your chair?
- **Nature:** have you thought about how you can bring nature into your home? Can you get some seeds and planting equipment delivered, or put up photos of green spaces?
- **Entertainment:** have you thought about things to do, books to read or TV shows to watch?
- **Relax:** have you got materials so you can do something creative, such as pencils and paper?



## Find ways to spend your time

- Plan how you will spend your time. It might help to write this down on paper and put it on the wall.
- Try to follow your ordinary routine as much as possible. Get up at the same time as normal, follow your usual morning routines, and go to bed at your usual time. Set alarms to remind you of your new schedule if that helps.
- Try having a clear out. You could sort through your possessions and put them away tidily, or have a spring clean.
- You could also have a digital clear out. Delete any old files and apps you don't use, upgrade your software, update all your passwords or clear out your inboxes.
- Build physical activity into your daily routine, if possible. Most of us do not have exercise equipment like treadmills where we live, but there are still activities you can do.

- Write letters or emails, or make phone calls with people you've been meaning to catch up with.
- Use different ways to relax, take notice of the present moment and use your creative side. These include: arts and crafts, such as drawing, painting, collage, sewing, craft kits or upcycling, DIY, colouring, mindfulness, singing or listening to music, writing, yoga, meditation, playing games e.g. jigsaws, crosswords etc

**Bringing nature into your everyday life can benefit both your mental and physical wellbeing. It can improve your mood, reduce feelings of stress or anger, and make you feel more relaxed.**

**It is possible to get the positive effects of nature while staying indoors at home. You could try the following:**

- Spend time with the windows open to let in fresh air.
- Arrange a comfortable space to sit, for example by a window where you can look out over a view of trees or the sky, or watch birds and other animals.
- Look at photos of your favorite places in nature. Use them as the background on your mobile phone or computer screen, or print and put them up on your walls.
- If you have safe access to green space like a garden, you could bring some natural materials in to decorate your living space, or use them in art projects. This could include leaves, flowers, feathers, tree bark or seeds.
- You may be able to buy seeds, flowers or plants online for delivery, to grow and keep indoors.

# Patient Stories

## HAYLEIGH

I'm Hayleigh. I am the Support Services Coordinator at The Paul Popham Fund and a patient on Nocturnal Haemodialysis.

I'm also a counsellor and am studying at university.

This situation has been very strange for me and my family. To protect my health I have been working from home since March.

All of my work, counselling sessions and university lectures have been moved to telephone or online, which has taken some time to adjust to.

My partner (a flooring contractor) stopped work mid March and our son has also been home from school from the same time.

We have all been isolated for about seven weeks and counting, and are having to rely on family members to deliver our food and supplies.

As a family we've had to make a lot of changes to our lives during this time and are still getting used to these.

But we've found lots of creative ways to maintain a sense of normality.

We are keeping in touch with family and friends through phonecalls, Facetime and Zoom and have even played monopoly with family through video calls.

We've also been sending and receiving small gifts and cards from family members to help us feel connected to each other.

We've spent a lot of time in the garden as the weather has been so lovely and are trying to keep active by following the Joe Wicks P.E. sessions on YouTube. We've baked cakes, completed two large jigsaws and done lots of arts & crafts. Yesterday we collected pebbles from the garden and are planning on painting them!

I'm very lucky that I am able to perform my dialysis treatment at home. This means that I have been able to minimise my contact with other people and have been able to stay away from the hospital.

I'm looking forward to being able to go out in public after this is all over and can't wait to go to the beach to walk barefoot in the sand.

## JULIE

I'm Julie, I am 2 years post transplant and on week three of self isolating.

I just treat everyday like I would normally do. My wonderful children and grandchildren facetime and we have had so much fun having quizzes and even bingo. We also had a scavenger hunt over Easter.

We can get through this. Positive thinking and following the advice we are given, and not forgetting the husbands, wives or partners who are helping us.

## DAVID

The most important thing for me in self isolation is to remain positive.

I use the extra time to my advantage, ringing family and friends more often, doing more exercise and keeping my mind active through quizzes, puzzles and reading more. Gardening and walking in the garden ensure I get fresh air.

Food deliveries are a problem and is something that must be improved, I'm lucky I have good neighbours that I have to rely on. One change not made is to watch television in the daytime, which I've never done.

## JOE TOWNSEND

On the 19th of March I got told I should not be working due to covid-19.

At the time I was on front line working on the ambulances and love my job. So my company agreed with the doctors and told me to stay off for 12 weeks, I am now furloughed. I didn't think I would cope as I'm always working or out doing things with my family. But I have found things to entertain myself and my two boys, one 4 and the other 2. We are home schooling and learning a lot. We have planted sunflowers and the garden is looking good. I've also never cleaned my house so much before.

Lego has helped a lot as I'm big lego fan so that keeps me going. I do a lot of exercise so do the Joe wicks workout every morning. I've also been set a challenge to do 60 push ups a day for 12 weeks - I'm going to be a new man after these 12 weeks.

I also set myself goals to do every day and put them on the calendar for the week. On a Sunday I sit down and think of more goals and things to do. And keep having a laugh. Keep safe everyone.

## Kidney Wales Team Update

Kidney Wales has been affected significantly by the outbreak of the Coronavirus pandemic. Unfortunately, as a result of this, the decision has been taken to place some of our employees whose work is directly affected by the Coronavirus outbreak on a period of Furlough Leave. This includes our two Patient Advocates, Shaun Ruck (South Wales) and Brett Dowds (North Wales). In their absence, please contact Judith Stone on [judith@kidneywales.cymru](mailto:judith@kidneywales.cymru) or phone 029 2034 3940.

You can also sign up to receive information from Kidney Wales via our website; join our Kidney Wales Facebook Community; and follow us on Facebook, Twitter, Instagram and Linked In.

# Stay Active at Home

With an indoor lifestyle, physiotherapists recommend a few simple steps to help you stay active at home, lift your spirits and reduce stress. Try them at least twice a week - or even better, daily!



## SIT TO STAND

Sit tall near the front of a chair with your feet slightly back. Lean forwards slightly and stand up (with hands on the chair if needed). Step back until your legs

touch the chair then slowly lower yourself back into the chair. **Repeat 10 times.**



## HEEL RAISES

Stand tall, holding the back of a sturdy kitchen-type chair or kitchen sink, then lift your heels off the floor, taking your weight onto your big toes. Hold for three

seconds, then lower with control. **Repeat 10 times.**



## TOE RAISES

Stand tall holding the same support, then raise your toes - taking your weight on your heels. Don't stick your bottom out. Hold for three seconds, then lower with

control. **Repeat 10 times.**



## ONE LEG STAND

Stand close to your support and hold it with one hand. Balance on one leg, keeping the support knee soft and your posture upright.

**Hold the position for 10 seconds. Repeat on the other leg.**



## HEEL-TOE STAND

Stand tall, with one hand on your support. Put one foot directly in front of the other to make a straight line. Look ahead, take your

hand off the support and balance for 10 seconds. Take the front back to hip width apart. **Then place the other foot front and balance for 10 seconds.**



## HEEL-TOE WALKING

Stand tall, with one hand on a support like a kitchen cabinet. Look ahead and walk 10 steps forwards, placing one foot directly in front of the other so that the

feet form a straight line. Aim for a steady walking action. **Take the feet back to hip width apart, turn around and repeat the steps in the other direction.**

● Make sure the chair you use is sturdy ● Wear supportive shoes. ● If you experience chest pain, dizziness or severe shortness of breath, stop and contact a healthcare professional ● A slight soreness the day after is quite normal. [www.csp.org.uk/easyexercises](http://www.csp.org.uk/easyexercises)

## GERAINT JOHN

'A bit different' Well, my birthday this year certainly was that.

April 3rd 2020, was something of a milestone as I turned 65 and as with everyone else who has a birthday, anniversary etc., during these strange times, we realised that we were not able to actually hold a Party. So no family or friends to drink my beer and eat my food lol, perhaps its not that bad eh??

Hmmm, What to do?

So, instead of postponing to a later date we decided to hold a 'Virtual' Party.

Our eldest Son Rhys, his Husband Daniel and our grandson Bailey, living in Carwe, Carmarthenshire, along with our younger son Gareth, Dawn his Fiance and our 2 other Grandsons Trystan and Rowan living in Gorseinon, downloaded Zoom. This means we can all log-in at a given time.

It was a great success, our Grandsons aged 8, 5 and 2 being able to sing Happy Birthday along with each home having a cake, so candles were lit, the song was sung, candles blown out, the kids were excited, but not as excited as their Dadcu...

We had a fantastic time, only thing missing were the 'Cwtches'. When this is all over, we can easily make up for that.



## Anxiety first aid through Covid-19

We ALL feel anxious at the moment - it's understandable, it's ok, it's normal under the circumstances. These strategies can help:

- Focus on what you can control right now - stick to your plan for the day, do something you would normally enjoy; deliberately shift your attention away from threat-based concerns to something else.
- Take a moment to focus on your senses - SMELL, SOUND, TOUCH, TASTE, SIGHT. Close your eyes, be curious!
- Rest your attention on your feet - the ground is solid beneath you, take a breath, wiggle your toes. Simply notice your feet!
- Square box breathing helps - focus on any square wherever you happen to be - window, cereal box. Visualise breathing up one side, pause your breath along the top, breathe out along the third side, pause on the fourth. Just follow this rhythm for a while.
- 5 finger breathing can also help. With your left index finger trace the outline of your right hand. Breathe in as you travel up the little finger, down as you travel down and keep to the rhythm of breathing in & out as you follow the outline of your right hand. Do this with your eyes closed.
- Listen to music that soothes & calms - the Compassionate Mind Foundation have put together a helpful playlist on Spotify: CFT Compassion Songs.
- Do things that soothe you - a nice book, film, jigsaw - activities & stories that console, that take the edge off your anxiety.
- Release the anxiety through exercise, yoga, mindfulness, singing, creative writing, craft or something similar - try out the amazing online resources that have become available.
- Focusing in on threat fuels anxiety (worrying bodily sensations, the news, fake news). Focusing out is always more helpful!
- Do all this with kindness, acknowledge how you're feeling, that it's hard. Imagine how you would respond to someone else who was struggling & bring the same qualities of compassion & care to yourself! Remember you have resilience; you will get through!



## Wash your hands of coronavirus scams!

Friends Against Scams aims to protect and prevent people from becoming victims of scams.

### Be aware of people offering or selling:

- Shopping or medication collection services.
- Medical products, such as miracle cures, face masks and testing kits.

### Be aware of suspicious communications, such as:

- Impersonation of officials, including HMRC and government agencies.
- Subscription and streaming service emails prompting account updates or requesting personal details.
- Social media quizzes and games that ask for personal information (e.g. your mother's maiden name).

### Protect yourself and others:

- Don't assume everyone is genuine. It's okay to reject, refuse or ignore requests for personal or financial information. Only criminals will try to rush or panic you. Check with family and friends before accepting offers of help if you are unsure.
- Only purchase goods and services from legitimate retailers. Do your research and take a moment to think before parting with money or personal information.
- Only use official websites, such as **gov.uk** for updates and information, and avoid clicking links in unsolicited emails and messages.
- Be suspicious of requests for updating your account details. To check or update accounts, always go directly to the organisation using the website or contact details you know to be genuine.
- Be aware of the amount of personal information you share on social media; not all quizzes are harmless.

Be a good Friend,  
help to protect  
your family,  
friends and  
neighbours from  
scams.

Read it.  
Share it.  
Prevent it.

#ScamAware  
#Coronavirus



### Contact:

For advice on scams, call the  
Citizens Advice Consumer Helpline on **0808 223 11 33**.  
To report a scam, call Action Fraud on **0300 123 2040**.  
Contact your bank if you think you have been scammed.

**NATIONAL  
TRADING  
STANDARDS**

Scams Team

To learn more about different types of scams, visit: [www.FriendsAgainstScams.org.uk](http://www.FriendsAgainstScams.org.uk)

## COMING SOON

### Treatment Options for Home Dialysis

The Paul Popham Fund will be holding a Q&A with Hayleigh Isaac, Support Services Co-Ordinator, PPF and Gail Williams, Lead Nurse, Welsh Renal Clinical Network. The session will be a general overview of home therapies with a focus on home haemodialysis.

**Back to basics;** Kidneys keep the balance of water and chemicals in the blood, this is called **homeostasis**. When they kidneys fail, fluid and chemicals build up in blood and people become unwell. **Dialysis** is one treatment for kidney failure. This is an artificial way of removing waste products and water from the blood. There are **two types** of dialysis:

**Peritoneal** - this type of dialysis happens inside the body, using a natural lining within our abdomen called the **peritoneum** which has the ability to adapt and to act as a filter to remove toxic waste and fluid.

**Haemodialysis** - this type of dialysis happens outside the body, using a **machine** and an artificial kidney called a **dialyser** to act as filter to remove waste products and water.

**The great thing about both types of dialysis is that they can be provided safely in the comfort of your own home.**

The Q&A will explore the benefits of dialysing at home from the personal perspectives of Gail and Hayleigh.

This will be taking place via the Paul Popham Fund, Online Support Group; Home Therapies Kidney Café. This is the link to watch the Q&A:

<https://www.facebook.com/groups/hometherapieskidneycafe/>

### Advanced Care Planning - An Introduction

The next edition will provide practical information on how Advanced Care Planning supports patients, families and the renal professional team - The term Advanced Care Planning (ACP) is used to describe conversations about future care with health and social care professionals. It is a communication plan that can be used in the event a person can't speak or make decisions for themselves. ACP is not new to renal care, many patients have written their preferences, wishes and have gained comfort knowing that their family and health professionals know exactly what their wishes are. The next edition will provide practical information on how ACP supports patients, families and the renal professional team.



## Dr Mike Stephens answers your questions about Coronavirus

On 30 March, Dr Mike Stephens Consultant Transplant Surgeon at The University Hospital of Wales teamed up with Kidney Wales to host a live Q&A within the newly set up group on Facebook Kidney Wales Community.

### KEY MESSAGES INCLUDED:

- Wash your hands regularly with soap and water!
- Don't wait for your letter from the NHS - evidence shows that shielding works, do it now and stick with it! You will significantly lower risk of getting the virus
- If you are shielding, people you live with must stringently follow social distancing guidance
- Let your kidney team know if you have any symptoms and they will keep a watch on you
- Don't make any changes to your medication unless you are advised to do so by your kidney team
- If your kidney team ask you to attend an appointment at clinic, it is important that you are seen in person
- Some outpatient appointments may be less frequent or may be conducted over the phone
- The UK transplant programme is currently on hold
- Live kidney donors are not at higher risk of either getting the virus or having a more serious illness
- Take a look at the detailed Coronavirus guidance for people with kidney disease, produced by Kidney Care UK

**You can read a full report of the questions and answers here:**

<https://www.kidneywales.cymru/news/2020/03/31/dr-mike-stephens-live-qa-30th-march-2020/>

Or view the recorded Q&A session on the **Kidney Wales Community Facebook group**

## Recipe of the week!

**Kidney Care UK have a Kidney Kitchen section on their website, with a wealth of kidney friendly recipes. This newsletter will feature a new recipe in each edition, to give you inspiration for things to try at home.**

This idea has been chosen because it uses store cupboard items - and may be something fun to bake while staying at home!

### Pineapple upside down pudding:

#### INGREDIENTS

- Topping
- 50g unsalted butter
- 50g light soft brown sugar
- 9 x pineapple rings in fruit juice
- 9-10 glace cherries
- Cake
- 150g soft unsalted butter
- 150g golden caster sugar
- 150g self-raising flour
- 1.5 teaspoon baking powder
- 3 eggs

#### METHOD

1. Heat oven to 180C / Fan 160C / Gas 4.
2. To make the topping, beat the butter and soft brown sugar together until creamy, spread over the base and up sides of a brownie pan or well-greased tray.
3. Lay 8-9 pineapple rings in the base of the pan and place the glace cherries into the gaps. Put the syrup aside to use later.
4. Add the rest of the ingredients into a mixer along with 3 tablespoons of pineapple syrup and whisk until a soft consistency.
5. Spoon the mix into the top of the the pineapple rings and smooth over until level.
6. Bake for approximately 35 minutes, remove from the oven and leave to stand for 5 minutes.
7. Turn out and serve

## Useful Resources & Contacts:

**Paul Popham Careline:** Speak to fellow kidney patient for advice and support or access counselling. Call: **0800 0388 989**

**The C.A.L.L. Helpline:** A dedicated mental health helpline for Wales. Call: **0800 132 737** or text **'help'** to **81066**.

**Mind Cymru Infoline:** For information on types of mental health problems, where to get help, medication, alternative treatments and advocacy. Call 24/7: **0300 123 3393**.

**Citizens Advice:** Provides advice on financial support and can signpost you to other agencies who may be able to help you. Call: **03444 77 20 20**

**Samaritans Cymru:** Offering a safe place for you to talk any time you like, in your own way - about whatever's getting to you. Call 24/7 for free on **116 123**.

**Womens Aid:** For help if you are experiencing domestic abuse/violence. If you need help and support for yourself or for someone you know, please call or email the Live Fear Free Helpline **0808 8010 800**.

Renal Social Worker's across Wales continue to be available to support individuals and families. The only change is that some maybe working remotely. Please contact directly, or ask a member of staff to refer.

**University Hospital Wales:**  
Laura McGuinness Tel: **02921 844 124**.

**Ysbyty Gwynedd:** Alison Richards  
Tel: **01248 363469**.

**Ysbyty Glan Clwyd:** Jayne Davis  
Tel: **01745 448778 ext. 2508 / 07773 107444**

**Ysbyty Maelor Wrexham:** Andrew Barnett  
**01978 727296 / 07583 069908** or  
Caron Jones: **01978 727296**.

Morrison are currently without dedicated renal social work support, please contact **Paul Popham Fund** or **Kidney Care UK** advocate for advice/support.