

Kidney patient Covid-19 update

ISSUE 3
JUNE 2020

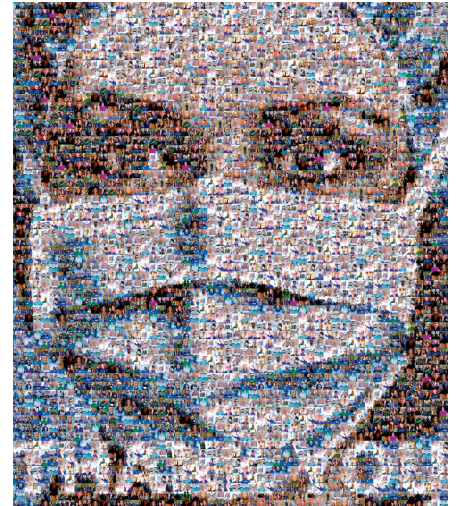


Welcome to the third edition of your kidney patient newsletter. We hope this update finds you well. In this issue we share ideas and resources for staying connected in isolation, talk about important decision making processes and share more helpful tips and guides for your wellbeing while in lockdown.

This newsletter has been compiled by Kidney Care UK, Kidney Wales, Paul Popham Fund, the Welsh Clinical Renal Network which oversees services for adult kidney patients in Wales and the Wales Kidney Research Unit (an All-Wales strategy for the study of diagnosis, prevention, treatment and social context of kidney disease). We value your opinion and would welcome

your feedback on the content, what you would like to see now and in the future. This is your newsletter and it is important that it works for you. You can feedback through your kidney care team or contacting any of the charity providers on the details below. Please help us in continuing to thank our renal health and social care workers by sharing your stories, photos, artworks, poems with us. Specially designed certificates of thanks are available from us - send one to someone who deserves a special mention today. We will publish them online and on our social media.

This newsletter is available in Welsh so if you would prefer that, please ask a member of your kidney care team.



Find out what's on in Wales during isolation

Isolation is challenging everybody. It is especially hard for kidney patients. It can lead to low energy, boredom and anxiety, having huge impact on mental health and wellbeing. We have compiled some ideas that go beyond a video call, and share resources of 'virtual socials' taking place. It is really important that we feel connected, even while we are apart.

- **Host a virtual quiz:** You can create one yourself or there are 1000s free online. Simply agree a time, send out invites, ask a person to be the quizmaster. An online voucher could even be the top prize!
- **Watch Netflix with friends:** Netflix's new Party feature makes watching a movie at home more like a cinema experience. The new feature allows you to host long-distance movie nights, synchronising video playback and adding group chat to your favourite titles.
- **Watch live music:** There is nothing like a live performance. Many artists are planning to livestream DIY gigs direct to your living room completely free. Examples include Manchester music venue Jimmy's isolation gigs and the Metropolitan Opera's daily encore presentations. Google to find many many more!
- **Make art with friends:** Pick a theme, give people a deadline to paint, draw, write, choreograph etc. Send in your submissions and have a judge decide the 'best in show'.

- **Live stream a fitness class:** Video channels are full of free home workouts now. Many big gym chains are also streaming live workouts so you can still 'get that gym feeling', whilst at home.
- **Host some virtual celebrations:** There are many apps available which can make it feel like you're enjoying each other's company as though you're all in the same room.
- **Cook together:** Why not try a new recipe with friends. Agree a recipe, set a time and cook it together. It will be fun comparing how each of yours comes out!
- **Create a self-isolation picture diary:** Although many of us might want to forget this time. Many people are getting creative and sharing funny and moving images of living in isolation, so they can look back on the positive memories.



- **Learn a new skill:** Whether it is learning to cook, play an instrument or even learning a new language. Britishsign are hosting a 'pay what you can scheme' over Covid-19. Why not learn the only universal language.
- **Sign up for 'secretsofa':** Visit secretcinema.org. Shhhhh tell no one!
- **Become an interior designer:** We are seeking to redesign some of the dialysis training areas and we need your help! Find out more here (www.youtube.com/channel/UCuMnTURP10rWTuKw9Y_eu-A?view_as=subscriber)
- **Get involved in research:** The Wales Kidney Research Unit has lots of ongoing projects that still need your input. We have created virtual webinars that you can contribute to. Find out more here (www.youtube.com/watch?v=eulfFW4PjAk&t=21s)
- **Fundraise:** Your local kidney charities need you more than ever before. Consider hosting any of the above as a fundraiser to support the work they do for you.

You can also go online to their websites and take part in their virtual social events.

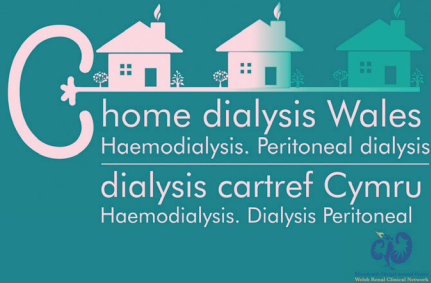
Have you hosted or taken part in a virtual social? Are you celebrating a 'big day' perhaps a 'kidneyversary'. Let us know and we can feature it here.

Shared Decision Making

Shared decision making is a collaborative process through which a healthcare professional supports a patient to reach a decision about their treatment. The conversation brings together:

- the healthcare professional's expertise, such as treatment options, evidence, risks and benefits
- what the patient knows best: their preferences, personal circumstances, goals, values and beliefs.

Shared decision making is a key component of Universal Personalised Care and will be very important to you at various stages of your future care planning.



Home therapies allow you to carry out your kidney treatment in the comfort and safety of your own home.

Home dialysis (for those where it is clinically safe) can offer so many benefits. Hayleigh Isaac, a kidney patient receiving a home therapy treatment, Gail Williams, Lead Nurse, Welsh Renal Clinical Network and Joanne Popham family member of a kidney patient and CEO of Paul Popham Renal Fund recently sat down to talk about pros and cons of home dialysis. You can watch their Q&A session here: paulpophamfund.co.uk or on their Facebook page from June. We share some of the 'best bits' for you below.

- This disease and its treatment are life changing, think about how dialysis will fit into your life and allow you to live the best life possible. Speak to kidney patients or 'peers' who are on home therapies.
- It is important to remember that a dialysis plan is needed, even for those who choose a kidney transplant, just in case dialysis is needed before a kidney becomes available. A treatment plan is needed, similar to a birthing plan for mums to be.
- For many, it's a shock to be told that their kidneys are not working sufficiently. At this stage, it's really hard to imagine being on dialysis, people are understandably worried and anxious.
- Please be assured, home dialysis is safe. In fact during the pandemic it has provided safe treatment with less exposure to the virus compared to people having to leave their homes for their dialysis treatment.
- It offers flexibility for more treatment, either in frequency, hours or a combination of both.
- Think of the skill needed to drive a car, think about what it must feel like for the first time, sitting in the machine, a car. Any skill can be learnt and mastered by practice, repetition and support. Anyone can learn to drive a dialysis machine competently and successfully.
- We've actually worked out that over the last 9 years I have performed over 2800, receiving over 22,400 hours of dialysis. A patient in a hospital or unit would have to dialyse for 36 years to receive this much dialysis.
- On a home Haemodialysis therapy, a different needling technique is used and is more like putting an earring in.
- Explain about the treatment to family, children and friends, give them a chance to ask questions, reassure them that you are receiving good treatment and its keeping you well.
- People describe adapting to home dialysis like being home with a new baby. Getting used to new things, learning new routines and making adjustments etc. Once things settle down, the dialysis routine becomes second nature.
- Everyone deserves a holiday and being on dialysis should not be a barrier to this, I have been to Europe, London and Butlin's many times while on home dialysis.
- Peritoneal dialysis offers the flexibility of holidays. The dialysis company will deliver the dialysis fluid to your holiday address, this could be abroad, a cruise ship or even a static caravan. If you have a motor home, or just fancy a weekend away, fill the boot of your car up and away you go!
- I think that we will all agree (especially in these times) that time is precious. Dialysis at home, at night, whilst asleep, is no brainer for me. Every day becomes a treatment free day. Precious time to enjoy with family and friends, time to enjoy hobbies, time to work or even study and time to go on well-deserved holiday.
- Paul Popham Fund have built services that provide patients with a community of support to access so that they do not feel isolated or that they are on their own. We have a Peer Support Service where patients can talk to other patients who have lived experiences of the different aspects of kidney failure, they are leading a full life, they have been trained as a Volunteer Peer Mentor and therefore understand what others maybe feeling and can offer support.
- We have informal support groups called Kidney Cafes where people with kidney disease can meet others, learn from each other and gain some education. During this time our support groups are all online, and can be accessed via our website (paulpophamfund.co.uk).

advance renal care planning
future renal care planning

think
talk
share

Start the conversation
If you would like to know more about
advance/future renal care planning
speak to a member of your renal team today



If COVID 19 has taught us anything it is that you never know what is around the corner. Advance Care Planning contrary to what you might think is about planning for your LIFE, and EVERYONE needs to start thinking, talking and sharing.

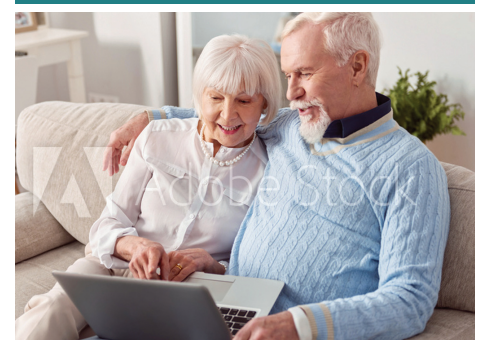
A very small part of this process is about planning for what you want to happen if you become too unwell to speak for yourself, and for you to have the opportunity to say what you want your end of life care pathway to look like.

Many people initially feel uncomfortable at the thought of having these conversations and they are difficult. They can feel taboo or unnatural. Even Doctors and Nurses can shy away from them feeling guilty or anxious bringing up the topic. COVID 19 has tragically meant that many people are dying alone in hospital without their loved ones present.

When healthcare professionals have to call and ask about an Advance Care Plan families become deeply distressed and feel helpless as they have never talked about what their end of life care plan looks like.

'We all need to be better at letting those around us know what we'd want, what we would not want, when we become too unwell to talk for ourselves' Patient

The next newsletter will continue this discussion.



Face Masks

This is to protect you and your key workers. The aim is to minimize risk of direct/physical contact between you and your key workers, and to minimize the risk of indirect/environmental contact, i.e dialysis equipment, the machines, chairs etc. It might seem a little strange at first but they are there for your benefit. If you have any concerns please contact a member of your kidney care team.

During these times we also need to remember that it is OK not to be OK.

If you are feeling anxious, depressed or suicidal it is important that you reach out as soon as possible. This might be to a family member, friend or health and social care professional.

it's okay
not to be
okay

There are lots of Independent services out there now who are specially trained to help.

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.

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.

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

Women's 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.

CRUSE bereavement Care: Free helpline, 0808 808 1677

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

How to get to sleep

'A sleep hygiene guide for anxious times.' During times of prolonged worry it is very normal for people to experience sleep disruption.

These seven suggestions might help you to get a better nights sleep.

1. A good nights sleep starts in the day.

There is a lot you can do during the day to help your nighttime sleep - making your bed in the morning, doing daytime physical exercise, and getting some sunlight can all help. Daytime naps should be limited. Avoid alcohol, caffeine, nicotine and rich foods in the evening.

2. Protect your sleep space

Try to make your sleep space as calm and uncluttered as you can. It also helps if your bedroom is dark and cool. Your bed should be used for sleep and sex only, so keep other activities like working from home out of the bedroom wherever possible.

3. Switch it off

Looking at mobile phones and other electronic devices at night disrupts sleep, particularly during times of high anxiety and increased news traffic. Try to stay off your phone for at least one hour before bed, and use function such as 'do not disturb' to minimise nighttime disruption.

4. Get into a bedtime routine

Try to establish a regular bedtime and nightly relaxation routine. This could include having a warm bath or shower, doing some gentle stretches, reading a soothing book, or practicing a relaxation or mindfulness exercise. Try to avoid upsetting conversations or news during your relaxation period.



5. Write down the worries

If you are finding that particular worries are keeping you up at night, it can be helpful to make a 'worry time' deal with your mind. Write down your worries in a notebook by the bed and agree that you will think about them in the morning - things tend to feel a lot less scary in daylight.

6. Relax your mind

Holding on to frustrations and tension will not help you sleep. Try practicing deep breathing and mindfulness exercises to help your mind switch off ('body scan' and 'leaves on a stream' are great exercises to start with and are widely available online).

7. Practice kindness

During times like these we all need some extra love and support. Focussing on feelings of love and compassion can help trigger your body's relaxation processes, so be kind to your mind, and send love to those around you.

Read more here:

[sleepfoundation.org](https://www.sleepfoundation.org),
<https://www.nhs.uk/live-well/sleep-and-tiredness/how-to-get-to-sleep/>

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.

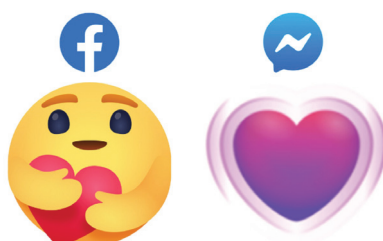
Morrison:

Please contact **Paul Popham Fund** or **Kidney Care UK** advocate for advice/support.

News...

Facebook have launched new 'care' reactions to help us stay connected.

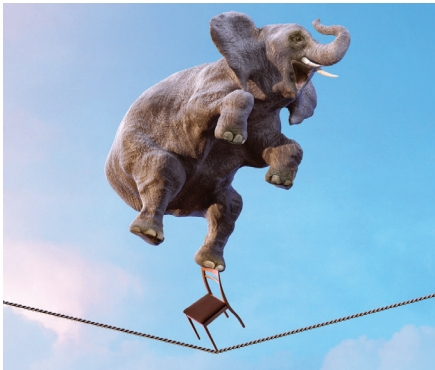
Be sure to download yours today.



It's all about balance

We know that things feel a little scary and uncertain at the moment. Your experience of living with a health condition and the stresses and uncertainties it brings will make you more prepared to cope with this situation than most people.

If you're finding yourself worrying, it might help to try to focus on the things that you can control in your life.



Things you CAN control. Focussing on these can help your body and mind - direct your attention here wherever possible.

Know your 'sick day rules'

If you have guidelines for managing your condition when ill, make sure you're up to date with them.

Check out your job policy

Regarding sickness/time off/working from home

Contact details

Make sure your contact details are up-to-date with your hospital / care provider

Know the symptoms of covid-19 and what to do

Use the NHS Direct website and follow guidance from your care team

Let your renal team know as soon as possible if you are experiencing symptoms.

Ask your renal team if you are unsure why they are asking you to change any part of your treatment or how you access it.

Take precautions

Give your body as much support as you can, by making sure you managing your condition as well as you possibly can do. Ensure you have supplies and repeat prescriptions up to date.

Look after your body

Try to make good food choices - this could be your chance to expand your cooking skills! Try to maintain a good exercise level and get sufficient sleep.

Look after your mind

Keep in touch with friends and family. If you're isolating, remember to care for yourself mentally

Say 'no' and ask for help

Feel confident in saying "no" and ask for help if you feel you need it

Wash your hands!

Regularly - 20 seconds with soap and hot water. Don't be afraid to ask others to do the same!

Things you CAN'T control. Focussing your worry on these won't change things - try to kindly redirect your attention.

Having a pre existing condition

This may make you more vulnerable to becoming unwell if you should catch the virus. But you can control your behaviour and actions e.g. shielding.

Other people's feelings, opinions or actions

Do what you are able to do and try not to get stuck in other people's ideas or behaviours

Who catches it

You do not have control over who catches it. Just try to be supportive and understanding for the people who do get COVID-19. It is not your fault if you catch COVID-19. Be kind and compassionate to yourself

Scare stories and the media

Get your news from reliable sources. It's OK to take a break from the news if it feels too much

Things getting cancelled

This can be really disappointing and a hard decision to make, especially if you are the one doing the cancelling, BUT do what is safe and what is needed

Your thoughts and feelings

Anxiety and worry is a completely normal response in the circumstance. You can't control your feelings, but you can control what you do with them.

What's in the shops

You can't control the availability of supplies. Try to be patient and try not to panic buy.

Availability of healthcare staff and appointments

It may be more difficult to contact your healthcare team or attend appointments. However, there are likely to be alternative options such as phone or Skype appointments

Needing to socially distance

If you have been advised to self-isolate and have to miss work, school or appointments; this is okay and the best course of action to look after yourself and stop the spread of the virus.

With thanks to @DrRoseStewart and @AugardeSophie for compiling and sharing this resource.

Take care of yourself



A healthy and balanced diet is an essential part of the treatment of kidney disease

Isolation can cause problems with sticking to a balanced diet as routines are so disrupted.

A renal dietician is a key part of your multi-disciplinary renal care team. If you need any help and support with managing your diet you can speak to your renal dietician who will be able to provide advice and support. To speak to your renal dietician just ask a member of your kidney care team.

A reminder if you cannot access food because you are shielding and cannot get anybody else to help FREE FOOD boxes are available. See gov.wales/getcoronavirussupport -extremely-vulnerable-person, for more information.

Coming soon: Empowering people with kidney disease, advance care planning and more helpful updates. Please get in touch if you would like to see any news or features in your newsletter. You can get in touch via any of the contact details below.

Finally Wales has a devolved healthcare system. It is important that you follow Welsh guidelines and updates. For kidney patients (for the moment) nothing has changed. All patients should be shielding until at least 15th June. Please speak to your kidney team if you have any questions about this.

For information & support

Team from Kidney Care UK

Head Office: 01420 541424

Wales Advocacy Officer: 01656 514776

E: Linzi.Isaac@kidneycareuk.org

Team from Kidney Wales

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E: team@kidneywales.cymru

Team from Paul Popham Fund

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