

# Kidney patient Covid-19 update



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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. In this issue we promote good news stories to help us remember to smile, describe the importance of Shared Decision Making and how it is used and share peoples experiences of doing an Advance Care Plan.

Help us in continuing to thank our renal community by sharing your stories, photos, artworks, poems with us. We will publish them online and on our social media. Send a 'thank you' today.

This newsletter is available online in Welsh. Ask your kidney care team if you would like a copy. Previous editions are also available online [www.kidneyresearchunit.wales/news.htm?id=94](http://www.kidneyresearchunit.wales/news.htm?id=94)

## An important reminder that Wales has a devolved healthcare system.

It is vital that you follow Welsh guidelines and advice in these unique times. We know that messages can still be confusing that is why you need to consult with your kidney care team if you are unclear about any Covid 19 updates.

Try and stay off social media and take regular breaks from the news if you are getting anxious or confused. Listen to your healthcare professionals they will have the most up to date guidelines for you and you alone.



## 'Good news': Stories from across the world to make us smile

In times like this it can be easy to lose sight of all the good things happening around us. We wanted to take a moment to share some of the good news stories from the across the world.

Perspective is important, take a moment each day to smile.

- **A poll of 2,000 Americans revealed 64% have had an 'eco wake up call'** This included becoming more aware of wasting food (44%), using paper products more sparingly (43%) and being more careful about where they buy meat (38%). These behaviours are also not likely to go away when COVID-19 does.

- **The World Health Organization says walking and cycling are considered the safest means of transport to reduce exposure to COVID-19.** So cities around the world have been building new cycling paths and scaling up their car-free street initiatives. Now, it looks like many of these environmentally friendly changes will be permanent.

- **Rival gangs in Cape Town agreed to an unprecedented truce and together bring food to the poor.** South Africa has seen a 75% drop in violent crime during the coronavirus pandemic. Now, rival gang members in Cape Town are teaming up to collect and distribute food and essential goods to those in need. Before the pandemic, South Africa had some of the highest violent crime rates on the continent. But now, new circumstances have created changes that are leading to a silver lining.

- **Pet ferret helped donate thousands of books to kids by finishing a full marathon in 3 weeks.** 'Bandit' the pet ferret managed to complete a full marathon by taking the challenge in his tiny stride and completing several miles per day alongside his owners. The project raised money for The London Children's Book Project and the At The Bus art charity. Both organisations are putting together bundles of books and creative resources that will be handed out to thousands of young people in the Oxfordshire area

- **After decades of work, scientists have mapped the entire surface of the Moon for the first time.** Have you ever wondered what kind of rocks make up those bright and dark splotches on the moon? Well, scientists have just released a new authoritative map to help explain the 4.5 billion-year-old history of our nearest neighbour in space.

- **Seagulls on empty Roman streets have rediscovered their wild side.** Rome has reported seagulls are helping keep the rat population under control as they inhabit streets for the first time in decades.

- **The World came together to celebrate Captain Tom's 100th Birthday and his £34m Fundraiser for the NHS.** In recognition of his spectacular achievement, the war veteran was officially promoted from the rank of captain to honorary colonel in a letter presented by Lt. Col Thomas Miller and approved by Her Majesty the Queen. He was also given a spectacular Royal Air Force flyby by a Spitfire and Hurricane over his home in Bedfordshire.

- **Beekeeper makes electronic music recorded from his hives to inspire love for pollinator populations.** This beekeeper has made a name for himself by using his electronica music to raise awareness about dwindling honeybee populations.

- **Instead of selling lemonade, boy sets up 'Drive-By Joke Stand' to spread laughter during quarantine.** Rather than spend his times indoors, a 6 year old boy decided to spread joy in his community by setting up a "drive-by joke stand" so he could make his neighbours laugh while respecting social distancing guidelines.

- **Wellbeing packs raising spirits for women and girls together in Pembrokeshire.** Action for Women & Girls Together offers support to vulnerable girls and women aged 12 to 21 years to support them to make better choices, build confidence, stay safe and raise aspirations.

- **Cardiff businesses help feed NHS heroes.** More than 25 businesses in the Cardiff and Newport area have joined the #helptheheroesdiff campaign to provide weekly food parcels to more than 600 staff across seven NHS hospitals in Wales.

- **Wales is building a National Forest that will span the length and breadth of the country.** As a particularly mystical part of Great Britain that is home to a rich collection of folkloric fables (we even have a dragon on our flag), Wales is exactly the place you'd want to go if you were looking to find an enchanted woodland. The Welsh government is now working to plant a national forest that would run the length and breadth of the land.

All content in this feature has been taken from the 'Good News Network'. Read more good news stories on their website [www.goodnewsnetwork.org](http://www.goodnewsnetwork.org). Do you have a good news story you would like to feature in this newsletter? Get in touch to tell us about it. We can print it here alongside any images you have permission to reproduce.

# Future renal care planning/ advance renal care planning

You may have heard of this before and you may already have an Advance Care Plan (ACP). Wales is part of the global health and social initiatives to introduce ACP into all care pathways.

In fact Wales is leading the way, even producing plans and guidance for people who already lack capacity and those considered very vulnerable to have a say in what they want and do not want in their End of Life Care.

ACP is about planning for your LIFE and in particular what happens if you have a sudden serious injury or illness and you become unable to make or communicate decisions on your own.

ACP is a JOINT responsibility of patients, relatives and healthcare professionals to produce together. It can be revisited or amended at anytime and will only be referred to if you become unable to communicate for yourself.

We know that patients and family members who have produced an Advance Care Plan feel comforted, reassured and empowered: patients know their wishes will be followed;

family members know what their loved ones want and professionals know that they are acting in the best interest of their patients. Yet in spite of this, ACP is not yet a normal part of renal patient care.

Covid 19 has very sadly highlighted this important gap and tragically meant that many people have died without an ACP or their loved ones knowing what their end of life wishes were.

## Renal Social Worker Caron Jones shares her thoughts on doing an ACP.

*'Many people fear the thought of a medical emergency or a life threatening illness, not being able to communicate for themselves, and shy away from conversations around Advance Care Planning. Don't worry, Health Professionals can find this kind of conversation difficult too.'*

*End of Life is part of the cycle of life, communicating and recording our wishes for end of life care enables family members, and medical team, to strive to honour a person's wishes.*

*Gaining a person's knowledge and understanding of their medical diagnosis and overall wellbeing, is a good place to start a person-centred conversation. I ask people to think about what would be important to them should their health deteriorate and they be unable to talk for themselves.*

*I leave the ACP booklet with people to look through, and suggest they may want to discuss or complete with family members, good friend, or myself. I will return another time to revisit our conversation, and if required help complete the booklet. People can choose to complete as little or as much as they like. Once completed I will suggest the booklet be kept somewhere safe yet accessible, i.e. in the medication drawer.*

*We add ACP details to the information in the 'message in a bottle', which is placed in the fridge.' <https://lionsclubs.co/MemberArea/message-in-a-bottle> A sticker is placed on the reverse of the house door, also on the door of the fridge to alert emergency services the bottle exists. With the person's consent, I write to their GP and Consultant to make them aware that an ACP has been completed. Advance Care Planning is an opportunity for you to have your say.*



Talk to your kidney care team today about doing your Advance Care Plan. They will arrange it with you and whoever else you want to be part of it. Due to Covid 19 they will do this in a way that is safe - but do not wait to have the conversation.

We would like to know your experiences of doing your ACP.

### Some things to think about:

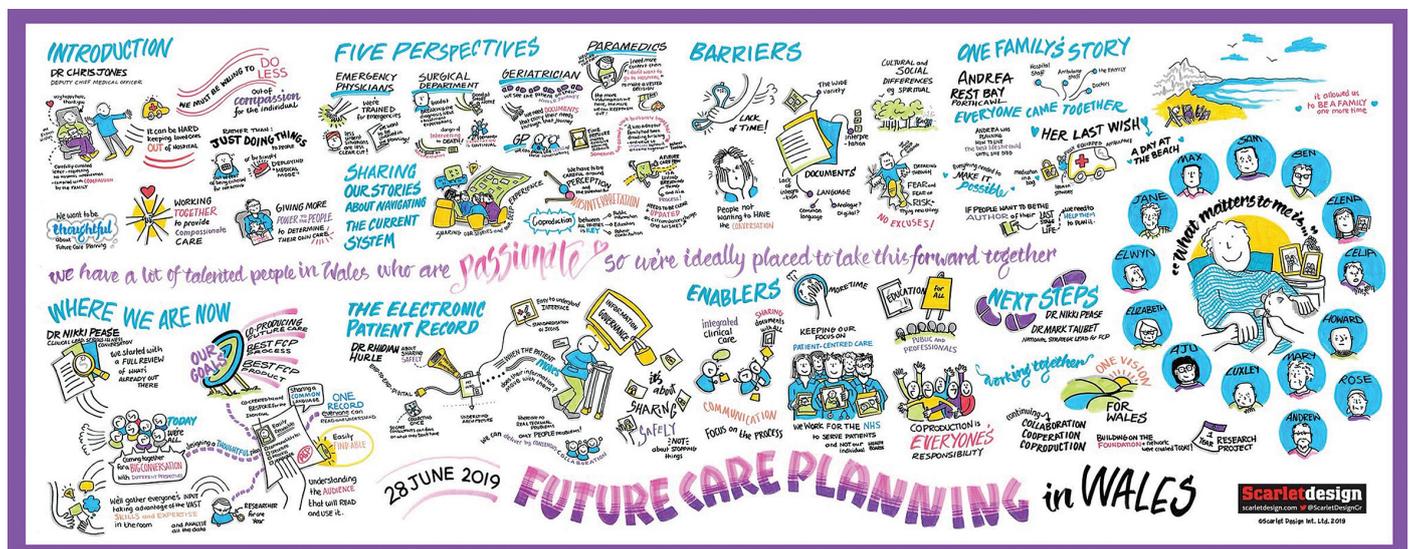
- Did you feel like it was your plan and tailored to you and your needs?
- Was the information presented clearly and you understood it?
- Did you find it valuable? What was the most valuable?
- How do you think we can make ACP a more normal and routine part of care?

This link shows some of the most recent guidance <https://www.nice.org.uk/about/nice-communities/social-care/quick-guides/advance-care-planning>

Wales is in the process of designing some new ACP documents and guidelines. We would like your help. There are various logos, brands and identities associated with ACP.

### What do you think about the draft?

Feedback via the contact details at the end of the newsletter.



## My Advance Care Plan Experience

Patient advocate and Kidney Wales employee Brett Dowds shares his experience of doing his Advance Care Plan.

*'A lot of people shut down when they hear about Advanced Care Plans (ACPs), as they don't like to think about them, however I have found having an advanced care plan to be a good way to keep control of my health and not leave my family with the responsibility of having to make serious choices on my behalf, if I was ever unable to do so myself.'*

*In N. Wales we have a simple booklet which breaks the process down into five sections. The first is about the ACP itself, sections two and three are about you and your health, the fourth is on whether you can make decisions for yourself and the fifth section is about what happens after your death. While this seems like a hard pill to swallow I personally found it very practical as it speaks about the importance of having a will, setting up funeral arrangements and nominating a person you can trust to have access to documents like your mortgage, passport, driving license etc.*

*The important thing to remember is that anything you put in here can be changed at any time as it is your plan - I find it very empowering to have full control over every aspect of my life.*

*Your ACP also does not need to be completed all in one go, you can take your time with it. Your kidney care team will have specialists in advance care planning and will be able to assist you'*

## Logo & poster?

Are you creative - we want your ideas for posters and branding.

We will be working to produce and modify guidelines, documents and plans over the coming months.

Please get in touch via the contact details below and share your vision for ACP in Wales.

The winning ACP poster or any modifications to the existing posters will be displayed in renal units clinics and in online portals across Wales. So don't delay share your Advance Care Plan today!



# Make No Decision About Me Without Me

We previously introduced the topic of Shared Decision Making (SDM) and stories about how patients have used it as part of their care, for example making decisions about their future dialysis treatment.

Shared Decision Making is for everybody and is such an important part of your care. You can help make Shared Decision Making a routine part of the culture of future kidney patient care.

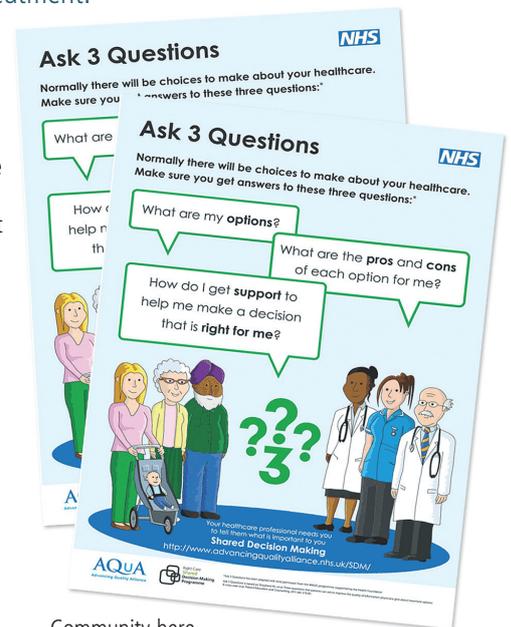
Shared Decision Making is simply a way to have more meaningful conversations with your healthcare professionals about your healthcare. It recognises that there are two experts in the room, your healthcare professional and you.

Some ways to start practicing Shared Decision Making are: Ask questions. You can prepare these in advance, discuss them at the time or at a later date.

Share your views and preferences.

This might include what is currently going on in your life or what you want in the future with your kidney care team.

Talk with your family, friends or other support networks. Shared Decision Making is about empowering you, highlighting that you have choices and options and working in collaboration. It is important that you feel you can talk about your needs with your loved ones and your kidney care team. There are some lovely videos and stories about how Shared Decision Making has helped patients and professionals online, one example is from the Bristol Health



Community here  
[www.youtube.com/watch?v=IZRUKF17zrE](http://www.youtube.com/watch?v=IZRUKF17zrE)

There are also various guidance and tools available to support Shared Decision Making. You can read more about these here  
[www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making](http://www.nice.org.uk/about/what-we-do/our-programmes/nice-guidance/nice-guidelines/shared-decision-making).

## Patient View

PatientView shows your latest test results, letters and medicines, plus information about diagnosis and treatment.

You can view PatientView from anywhere you want and share your information with anyone you want. Information comes directly from existing records, for example hospital and GP records, or may be entered directly or via other apps.

PatientView started out as a service for kidney patients in the UK but can now work for others too.

Speak to your healthcare team about how to sign up to Patient View.

**Judith Stone, CKD patient and Managing Director of Kidney Wales** says:

*'Patient View has been a game-changer for me. It has helped me learn more about my condition and to gain a better understanding of the different blood tests that are used to monitor progression of CKD. I have my bloods tested by my GP and can see the results on Patient View prior to my appointment with my Consultant. This has enabled me to prepare for appointments, mentally and emotionally, and to have a good quality, informed conversations with my Consultant. I'd encourage all patients to sign up'*



## Hand Washing

### You can play a critical part in fighting COVID-19

Hand Hygiene is one of the most effective actions you can take to reduce the spread of pathogens and prevent infections, including COVID-19 virus.

COVID-19 virus primarily spreads through droplet and contact transmission. Contact transmission means by touching infected people and/or

contaminated objects or surfaces. Thus, your hands can spread virus to other surfaces and/or to your mouth, nose or eyes if you touch them.

#### Wash your hands

- After coughing or sneezing
- When caring for the sick
- Before, during and after you prepare food
- Before eating
- After toilet use
- When hands are visibly dirty
- After handling animals or animal waste

Join the #safehands challenge now and save lives! Post a video or picture of yourself washing your hands and tag #safehands. Read more here [https://www.who.int/infectionprevention/campaigns/clean-hands/WHO\\_HH-Community-Campaign\\_finalv3.pdf](https://www.who.int/infectionprevention/campaigns/clean-hands/WHO_HH-Community-Campaign_finalv3.pdf)



## Post Transplant Kidney Café

### The next Post Transplant Kidney Café is on the Tuesday 15th July 2020

This month's theme is Mental Health and our guest speakers will be Catherine O'Leary, Maria and Misbah from the Renal Psychology Team in Cardiff and the Vale. Between them, they have many years' experience helping people to cope with the difficulties that can come from having chronic illness and related treatment.

To receive a link to the meeting please email: [support@paulpophamfund.co.uk](mailto:support@paulpophamfund.co.uk) or call 0800 038 8989

### All Wales COVID 19 Kidney patient survey

Kidney Care UK, Kidney Wales and Paul Popham Fund are working hard to support kidney patients in Wales through the coronavirus pandemic. We'd like to understand how COVID-19 is affecting your life to make sure we're supporting you as best we can and raising the most important concerns with Government and policymakers. Please let us know by completing the survey here by the 27th July: <https://surveymonkey.co.uk/r/N7Y7VY8>

## Kidney Services - Improving at Scale

'Learning from...Patients and Professionals working together to improve Kidney Care' With COVID -19 and the raised awareness of a lack of diversity in so many arenas it has never been more important than right here, right now, to involve patients in the improvement of health services. Join patients and professionals who discuss - with honesty - their practical experiences from four leading renal quality improvement programmes. This is the first in a series of #learningfrom webinars based on the outputs from the Health Foundation funded report 'Renal Service - Improving at Scale'. These activities took place in England but we are keen to apply learning to Wales.

If you are a patient, a carer, a family member or health professional who is involved in a service improvement or wanting to get involved and share your voice this event will be of interest for you. The Webinar takes place on 14th July 2020 from 5pm - 6.30pm. Register and further details here [https://us02web.zoom.us/webinar/register/WN\\_YI510LH1Rn-C\\_nuQEwD8FQ](https://us02web.zoom.us/webinar/register/WN_YI510LH1Rn-C_nuQEwD8FQ)

## Recipe of the week!



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 the lockdown.



## Summer Lemon and Pork Burger:

### INGREDIENTS

- 400g pork mince
- 50g white breadcrumbs
- 1 small onion, very finely diced or minced
- 2 level tsp fresh thyme and sage, finely chopped
- A pinch of freshly ground black pepper
- Zest of 1 lemon
- 1 egg
- 1 beef tomato, sliced
- 2 tsp olive oil
- 4 wholemeal rolls, cut in half
- 50g fresh rocket leaves
- 20g creme fraiche, to serve.

Visit the link below on Kidney Care UK for the method and more delicious recipes. <https://www.kidneycareuk.org/about-kidney-health/living-kidney-disease/kidney-kitchen/recipes/summer-lemon-and-pork-burger/>

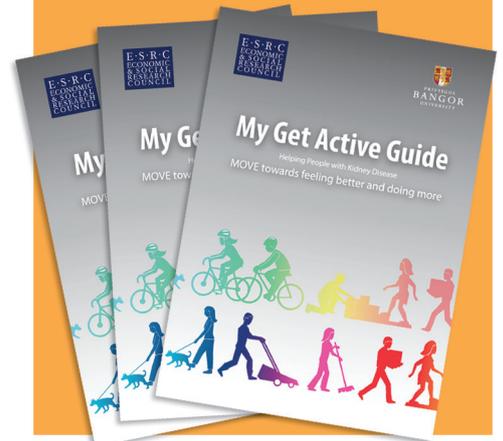
## Time to MOVE

Being physically active can be enjoyable and brings many health and wellbeing benefits. Some of you may have heard of MOVE or even been involved in the research.

They are a series of exercises specifically designed for kidney patients and includes resources tips for you and your health care professional. You can access the resources online here.

<http://move.bangor.ac.uk/index.php.en>. The websites includes videos and patient stories as well as examples of how to exercise.

The program is designed to help you recognise your current physical activity habits and to help you to become more physically active. As a person living with kidney disease exercise is a crucial part of your treatment as we are living in lockdown and with restricted movement, staying active and being mindful of your level of activity is very important. A physiotherapist is a part of your kidney care team. Ask a member of your team if you would like any advice or guidance.



## Coming soon...

Advice on **coming out of lockdown** and in particular **'un-shielding'**.

You can read some general advice here.

[www.theguardian.com/lifeandstyle/2020/jun/26/im-anxious-about-returning-to-the-world-after-lockdown-is-this-normal](https://www.theguardian.com/lifeandstyle/2020/jun/26/im-anxious-about-returning-to-the-world-after-lockdown-is-this-normal)

## 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)