

Kidney patient Covid-19 update



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Kidney Wales



Aren Cymru



Uned Ymchwil Arennol Cymru
Wales Kidney Research Unit



Rbyrdiath Glinigol Arennol Cymru
Welsh Renal Clinical Network

Welcome to the latest edition of your kidney patient newsletter. We hope this update finds you well as un-shielding commences across Wales.

In this issue we focus on the new normal and sign posting you to resources, information and networks of support.

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

Please enjoy this edition!

COVID-19: the 'new normal' for kidney patients

On 2 September 2020, Kidney Care UK, Kidney Wales and the Paul Popham Fund Renal Support Wales held their first collaborative virtual conference.



Until there is confirmation from Public Health Wales that the charities can organise and hold an official conference they have decided to organise a series of virtual conferences to keep you updated with the guidance and services available during this time.

The first virtual conference titled - **Covid-19 The New Norm for Kidney Patients**, created a space to share expert information and insight as Welsh Kidney patients come out of shielding.

Two speakers, **Fiona Loud**, Policy Director at Kidney Care UK, and **Dr Mike Stephens**, Consultant Transplant Surgeon at the University Hospital of Wales, delivered presentations and answered questions from participants.

Fiona Loud, started the conference by discussing the main concerns raised from a joint survey called 'Worried Sick' about the impact of COVID on kidney patients, which revealed:

- Difficulties with shielding in practice
- Negative effects on mental health and well-being

- Disruption to treatments
- Problems with accessing basic food and medicines
- Effects on household finances

As we move forwards, Fiona emphasised the importance of:

- Getting personalised advice and support from the NHS for your condition and how to best protect yourself
- Addressing physical and mental health needs- both are vitally important
- Having clear communication from government to shielding groups
- Ensuring continued access to food and medication
- Understanding what future local lockdowns might mean for shielding groups

Dr Mike Stephens followed providing information about the specific considerations for kidney patients in relation to COVID, with more detail for people who have received or are waiting for a transplant and when it may be advisable to self-isolate. He offered generalised advice regarding measures around returning to the work place (IF you're not able to work from home) and to school, and referred to the tools available from the Renal Association to assess levels of risk for different types of people for different activities, to help you make informed decisions about your lifestyle. Mike also spoke about progress with developing a vaccine. But in the meantime, both speakers emphasised the need to remain vigilant with social distancing and hygiene practices, while we begin to build confidence in a post-COVID world

To view the conference and access the full report visit www.kidneypatientconference.wales or contact one of the charities for a printed version of the conference report.

The charities are actively seeking ideas from patients for topics for future conferences, please do not hesitate to share your views.



PREMS

Your voice matters! Give us your feedback! Help us improve!

During the month of October 2020 if you are receiving dialysis at home, in hospital / satellite or a transplant recipient we really do want to hear from you.

We want to know about your own experience of care you are receiving - **PLEASE GIVE US YOUR FEEDBACK!**

In Wales, we want to continue to drive improvement to our renal service and we can only do this if we understand what is important to you - **YOUR VOICE MATTERS!**

Please help us to improve our service by completing the national on-line Patient Reported Experience Measure (PREM) survey. The survey is short and only comes around once a year, it's anonymous and focuses on your experience of your care. You are free to answer the survey as honest as you want without being identified - **HELP US IMPROVE!**

Please ask your dialysis unit, home therapies and transplant teams if you need any further information or support in accessing the survey. In fact, 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.

If you don't have access to the on-line survey because you don't have internet or a device, ask members of your family or your friends if they can help - we still want to hear from you.

<https://www.renalreg.org/projects/prem/>

Your questions answered from the conference



Is the process of applying for financial support and benefits going to be improved?

It's well known that it can take anything from 6-12 months

to apply and have a response for Personal Independence Payment. Even then you are not guaranteed to be accepted, which then requires an appeal process. In all this time, for many, zero money is coming in. The pandemic has shown to us as patients and the general public even more how serious kidney disease is and I think it's time that we didn't have to jump through so many hoops to prove how unwell we can be. Kidney Care UK has guidance on how to apply for PIP and our support

<https://www.kidneycareuk.org/newsandcampaigns/news/claimingpersonalindependencepaymentpip/>

Can you hug Grandchildren?

The guidance in Wales for children under 11 is to not maintain a social distance, so hugging your grandchildren is ok providing they wash their hands as soon as they enter your house and before you hug.



How do you monitor where you are on risk assessment?

Please speak to your consultant about your individual risk factors and discuss how these may impact on your treatment options and what sensible measures you can take to protect yourself. Use the Renal Association tool kit to choose lower risk activities.



NEW NORMAL



SOCIAL DISTANCING



WORK FROM HOME



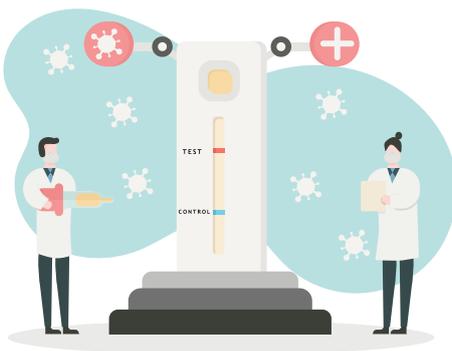
HAND WASH

What would be your advice for family members who have to go back to work who have been co-shielding?

Continue to work from home if you can. However if you must return to the workplace, it is the duty of the employer to make sure the environment is COVID safe. Explain to your employer that you live with a clinically vulnerable person, so that they understand your circumstances.

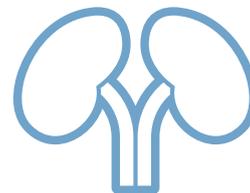
Should dialysis patients be getting tested weekly?

Public Health Wales are not advocating routine testing within units, unless clinicians observe symptoms that need to be checked. This is being kept under review, in respect of levels of virus within the community.



Can a donor still donate if they have antibodies but don't currently have the virus?

Transplant donors and recipients will undergo rigorous COVID and other testing in preparation for surgery to minimise the risk factors.



Will transplant patients be suitable for the COVID immunisation?



When a safe and effective vaccine is available, priority groups should be vaccinated as soon as possible, including people with chronic kidney

disease and solid organ transplant recipients. See interim government advice on priority groups for COVID19 vaccination:

<https://www.gov.uk/government/publications/priority-groups-forcoronavirus-covid-19-vaccination-advice-from-the-jcvi/interim-adviceon-priority-groups-for-covid-19-vaccination#vaccine-priority-groups-interimadvice>

Will transplant patients' family be on the top of the list for vaccines as well?

This information has not been made available yet.

Worried Sick Survey - Outcomes the main concerns raised and how charities can help?

Three quarters of patients felt lonely / anxious or isolated. Nearly half had serious concerns how lonely anxious or isolated they felt. While under a quarter said they did not have serious concerns there were still over a quarter who had some concerns.

There are many services out there specifically designed for Kidney patients, so you do not need to feel lonely or isolated during this time or any time:

- The Paul Popham Fund have a team of Peer mentors who have been trained to listen and talk to you at anytime. You can contact them via the Careline by calling 0800 038 8989 between 9am and 6pm Monday to Friday and talk to someone who understands. Or you can organise for someone to call you at anytime. Email support@paulpophamfund.co.uk and let us know your concerns and you will be matched to someone who has been through a similar journey. There is no need to feel lonely or isolated, pick up the phone for a chat with someone who cares!

- The Paul Popham Fund have various support groups that you can attend virtually during this time called Kidney Café's you can access these via the Paul Popham Fund Facebook page and search for groups or you can call 0333 2001 285 for further information.
- The Paul Popham Fund have a counselling service that you can self refer to or you can ask a nurse to refer you to. For further information call 0333 2001 285 or email support@paulpophamfund.co.uk



Nearly half found it difficult to access government support. This would have been easier if they knew that there were services out there to support them however over a half did not know there were volunteering services out there to help them or that they were eligible or how to contact them:

- The Paul Popham Fund have recruited a team of volunteers in Swansea who can support patients with food and medical deliveries, call 0333 20010 285 to access the Buddy Service.

In South Wales Nearly a quarter struggled financially 24% seriously struggled financially List of services and charities grant schemes to access for support.

- All three charities have a grant service that can support patients during this time.

Kidney Care UK has a counselling and support service that is available to all patients and their families. Call 01420 541 424 to book an appointment with a renal counsellor.

Employment Support for Kidney Patients

Scope (UK Disability Charity)

Support to Work: employment support programme

Support to Work is an online and telephone support programme for disabled people in England and Wales who are applying for jobs.

Eligibility

Support to Work is available to disabled people who:

- Are 16 years or over
- Are looking for a paid job
- Have internet, email and telephone or skype access
- Live in England or Wales.

Support Available

● Dedicated Employment Advisers

Specialist employment advisers can support with:

- Employability skills like time management and confidence
- Writing your cv
- Preparing for interviews.

● 12-Week Action Plan

Specialist employment advisers will work with you to create a confidential, personally tailored 12-week action plan. Your plan might include things like:

- Reading job seekers' advice
- Writing a cv or cover letter from a template
- Research for an interview.
- Your plan will be kept online, so you'll need access to the internet.

Your adviser will be on hand to help you throughout the 12 weeks. At the end of the 12 weeks you'll still have access to your plan and all its resources online.

● Online and Telephone Support

Support to Work is an online and telephone service, not a face-to-face service, which may not be right for everyone.

Contact

supporttowork@scope.org.uk or on 0300 222 5742 if you want to discuss whether Support to Work is right for you.

Careers Wales

Get help to write CVs, application forms, personal statements and more.

Helpful advice and tips on a variety of topics, such as:

- Building a cv
- Writing applications
- Covering letters and emails
- Interview techniques
- Personal Statements
- Assessment preparation
- Employment support
- Getting into self-employment
- Recruitment agency work

Contact

0800 028 4844 or visit <https://careerswales.gov.wales/getting-a-job>

Access to Work: Employment support

If you're disabled or have a physical or mental health condition that makes it hard for you to do your job, you can get extra help from Access to Work, including mental health support.

If the help you need at work is not covered by your employer making reasonable adjustments, you may be able to get help from Access to Work. You'll be offered support based on your needs, which may include a grant to help cover the costs of practical support in the workplace. Your workplace can include your home if you work from there some or all of the time.

Eligibility

To get help from Access to Work you must:

- Have a disability or health condition (physical or mental) that makes it hard for you to do parts of your job or get to and from work
- Be 16 or over
- Live in England, Scotland or Wales
- You also need to have a paid job or be about to start or return to one.

A paid job could include:

- Self-employment
- An apprenticeship
- A work trial or work experience
- An internship
- You cannot get a grant for voluntary work.
- Your job must be based in England, Scotland or Wales
- Certain benefits may affect whether you can get an access to work grant

Support Available

- Grants
- An Access to Work grant can pay for:

- Help getting to and from work
 - Adaptations to your vehicle so you can get to work
 - Taxi fares to work or a support worker if you cannot use public transport - for example, if you use a wheelchair and your journey includes a train station that does not have ramps
 - Taxi fares to work or a support worker if you cannot use public transport safely because of coronavirus (COVID-19) - for example, if you're blind and because of this you're unable to stay apart from other people
- Special equipment or software
- Adaptations to the equipment you use
- British Sign Language interpreters and video relay service support, lip speakers or note takers
- A support worker or job coach to help you in your workplace
- Personal protective equipment for your support worker, if you employ them yourself
- Disability awareness training for your colleagues
- The cost of moving your equipment if you change location or job

Access to Work can also help assess whether your needs can be met through reasonable adjustments by your employer.

● Mental Health Support



You can get confidential support and advice from a trained healthcare professional from the Mental Health Support Service. You do not need to have a diagnosed condition to use the service.

Contact

Access to Work helpline - 0800 121 7479
Apply online - <https://www.gov.uk/access>

Local Lockdowns and Me!

The Welsh Government announced it will implement its first local lockdown in Caerphilly 8th September following a rise in coronavirus infections.

People in the county borough will face new restrictions from 6pm on Tuesday due to the rise in Covid-19 cases.

The local lockdown will prevent people from entering or leaving the area without a reasonable excuse, they will only be able to meet outdoors, and everyone over the age of 11 must wear a face covering in shops.

What does this mean for Kidney patients if Local

lockdown happen in your area - Kidney Care UK provide the following guidance in England.

The UK Government have introduced new measures to deal with local lockdowns in response to local outbreaks, including giving local authorities powers to close specific premises and cancel events.

Infections may rise in local areas, and if so, depending on the severity of the outbreak, you may be asked to shield again. If this happens and you have previously been shielding, you should receive a text to let you know. You should then receive a letter outlining more information, which will also act as evidence to give your employers

'I am sticking with the shielding as I have before. Walking a bit more. Will stay safe'. Lesley Coles

so you can receive statutory sick pay. This advice is changing regularly and your local council website is the best place to keep an eye on. We have asked for more information about food and medication deliveries.

People in the clinically extremely vulnerable group should follow the same advice as the general population in their area.

Post-lockdown living donor pair celebrate Organ Donation Week 2020

In August 2020, Pembrokeshire couple, Rob and Christine Thomas, became the first live transplant pair to undergo surgery at the University Hospital of Wales since lockdown ended.

In 2010 Rob was diagnosed with Polycystic Kidney Disease (PKD) a genetic disease with no cure where kidneys grow to the size of rugby balls: "I was scared and upset. I'd never heard of PKD and when I looked for more information online, one of the first things I read is that I'd be dead within four years!". Rob's two siblings and his daughters have since tested positive for PKD.

Determined to get on with life, Rob remained active and healthy for several years. Rob has been a big supporter of Kidney Wales in the past, as the organiser of the Tenby 'Walk for Life' and he took on a 24 hour ride around Wales raising over £7,000.

However, a decline in his kidney function led to increasing tiredness, pain, infections, and ultimately, the need for a transplant.

Christine offered to donate straight away and thankfully she was found to be an excellent match. It was due to the strength of her decision that Rob found it easier to agree to it: "Had she been hesitant or scared, accepting her gift would have been harder, if not impossible". Christine explains: "We've always been open to discussing the issues relating to PKD, and not bury our heads in the sand when faced with the hard facts. This has helped us a lot."

Unfortunately, due to the strict measures in place at the hospital to protect the couple from Covid-19, Rob and Christine were unable to spend time together after their operations so they kept in touch via Face Time and WhatsApp. Since then,



there have been a few tears and sleepless nights, plus one readmission for Rob. But 4 weeks post transplant they are beginning to see progress, an easing of pain and a significant improvement to Rob's kidney function. Christine is taking three months leave from work, while Rob continues to shield and work from home: "I am to self isolate for a further three months due to now being immuno-suppressed, well until a vaccine is found in reality."

"My operation to transplant wasn't straight forward as I had to have an emergency operation straight after to reposition the kidney as it was compressed, but the team at The University Hospital Wales in Cardiff were and are amazing!"

For anyone considering living organ donation, Rob and Christine offer this advice: "Let the professionals deal with the technicalities and have the utmost faith in the surgical teams, as they're performing these operations daily. Be prepared to drink lots of fluid post transplant, expect the recovery period to be challenging, but know that progress will be made within a few weeks!"

Links to further information:

Across the UK, more than 1,000 people each year donate a kidney or part of their liver while they are still alive to a relative, friend or someone they do not know. The most commonly donated organ by a living person is a kidney. A healthy person can lead a normal life with only one functioning kidney and therefore they are able to donate the other to help someone in need of a kidney transplant.

<https://www.organdonation.nhs.uk/become-a-living-donor/>

September is also PKD Awareness Month with around 70,000 people affected in the UK. See: www.pkdcharity.org.uk



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. Try this sweet, delicious, classic dessert.



Creme Brulée

INGREDIENTS

- 500ml double cream
 - 2 vanilla pods
 - 100ml full-fat milk
 - 75g caster sugar
 - 5 egg yolks
 - 50g caster sugar, for topping
- Prep time: 15 mins
Cook: 2 hours 30 mins
Serves: 6



A smooth and sweet, classic dessert for a special occasion, try adding a small number of fresh berries for a splash of colour.

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

Coming soon:

Coming up in your next newsletter we have an update on home therapies, the impact of COVID-19 on the kidney population and the next steps to follow.

For information & support

Team from Kidney Care UK

Head Office: 01420 541424

Wales Advocacy Officer: 01656 514776

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Team from Kidney Wales

T: 02920 343940

E: team@kidneywales.cymru

Team from Paul Popham Fund

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