

# Kidney patient Covid-19 update



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Uned Ymchwil Arennol Cymru  
Wales Kidney Research Unit



Rheylwath Clinigol Arennol Cymru  
Welsh Renal Clinical Network

Welcome to our Christmas edition of this newsletter, where we reflect on the past year and share some ideas on how to keep well this winter and into the New Year.

The whole team would like to wish you a Merry Christmas and a Happy New Year.

Previous editions are also available online [www.kidneyresearchunit.wales/news.htm?id=94](http://www.kidneyresearchunit.wales/news.htm?id=94)

**We hope you enjoy reading this edition!**

## Looking Back at 2020

It's that time of year when most of us look back at the previous twelve months and set ourselves goals, or make plans for the year ahead.



2020 has not been the year that any of us expected, many of us had to cancel holidays, miss out on family events or had hopes of a transplant dashed. It hasn't been an entirely lost year though, the extended time at home during shielding and lockdown has allowed us all to explore new skills and hobbies; we've had more time to spend with loved ones at home, or virtually with those outside of our household; and it has revolutionised working from home for many.

The coronavirus pandemic may have stalled plans for the Wales Kidney Patient Conference, planned by the three kidney charities earlier this year, but we saw the regular patient information

newsletters come to fruition and many virtual events between charities, clinicians and patients to unite the Welsh kidney community.

As the darker evenings draw in and we make plans for a different kind of festive season, take some time to think about the things that have been positive this year; perhaps you've made a new friend or strengthened an existing relationship; you may have become more involved in your community; or been able to do things at home that you could never find time for before. For 2021 you could set yourself a resolution to continue with your new hobby, find a new one entirely, or speak to someone new at your unit.



## Christmas activities

With most seasonal activities cancelled this year, here are some ways you can stay in the festive spirit safely from home:

- Stream a pantomime online: There's no need to miss out this year, there are a number of shows you can stream at home at a fraction of the price of a standard family ticket. Simply search "pantomime online" to take your pick or watch the This Morning Pantomime for free on ITV from 10am on 11th December.
- Virtually browse a Christmas market: Independent retailers who would normally pitch a stall at your favourite markets can be found on [www.onlinechristmasfair.com](http://www.onlinechristmasfair.com) with plenty of discounts to be found.
- Watch a carol service online: Many churches have been live-streaming their services since the beginning of lockdown and continue to do so through the festive season.

Check your local churches website or social media to see if you can watch their services from home, if not Chichester Cathedral have a whole host of services planned from 19th December <https://www.chichestercathedral.org.uk/worship/liveservice>



- Track Santa: Not just for Christmas Eve, the [www.santatracker.google.com](http://www.santatracker.google.com) website is full of Christmas themed games and activities to keep kids (and big kids!) busy.
- Go sightseeing: pop out for a walk or a drive and look at all the Christmas lights in your community.
- In the kitchen: Try the recipe in this newsletter, or one of the many seasonal recipes from [www.kidneykitchen.org](http://www.kidneykitchen.org)
- Get crafty: Create some handmade cards, gifts or decorations this year. You'll find plenty of inspiration on [www.craftideas.info/html/cpi\\_winter.html](http://www.craftideas.info/html/cpi_winter.html)

- Organise a Christmas Jumper day: Whether you're at work, dialysis, or taking part in video calls from home; set a date for everyone involved to sport their best Christmas jumper to get in the spirit.
- The Parking Lot Social: There are a number of Christmas films, comedy nights and pantomimes that you can join from the comfort and social distance of your car between 9th and 13th December.

Visit [www.theparkinglotsocial.co.uk/christmas/sully/](http://www.theparkinglotsocial.co.uk/christmas/sully/) for details.

- Visit Santa by car: Santa's Drive-Thru Christmas Adventure will be at Wrexham until 20th December, where you can visit Santa and all his friends at the North Pole from the comfort of your car. Visit [www.eventbrite.co.uk/e/santas-big-drive-thruchristmas-adventure-tickets-120912166545](http://www.eventbrite.co.uk/e/santas-big-drive-thruchristmas-adventure-tickets-120912166545) to book
- Visit the Alpine Village in Swansea: With plenty of covid-safe measures in place, ride the 60ft big wheel overlooking the city and play all the games you'd usually find at the fair. Visit: [www.visitswanseabay.com/swansea-christmas/](http://www.visitswanseabay.com/swansea-christmas/) for details.



# Household bubbles for Christmas

All four nations of the UK have recently announced that current restrictions will be relaxed over the festive period.

HM Government NHS

## CHRISTMAS BUBBLE

Between 23 and 27 December you can form an exclusive 'Christmas bubble' of up to three households

Find out more: [gov.uk/coronavirus](https://gov.uk/coronavirus)

- Travel restrictions across the four nations and between tiers will be lifted to provide a window for households to come together between the 23 and 27 of December.
- Up to three households can form an exclusive 'bubble' to meet at home during this period. When a bubble is formed it is fixed, and must not be changed or extended further at any point.
- Each Christmas bubble can meet at home, at a place of worship or an outdoor public place, but rules on hospitality and meeting in other venues will be maintained throughout this period.

While we are all looking forward to being able to see friends and family for a short time, we must still be cautious and abide by social distancing and continue to follow all the existing regulations to keep yourself and others safe. Even where it is within the rules, meeting with friends and family over Christmas will be a personal judgement for individuals to take, mindful of the risks to themselves and others.

## Covid-19 vaccine Q&A

There is new information coming out daily relating to the COVID-19 vaccines.

There has been a lot of uncertainty in the kidney community and understandably a lot of questions too. Dr Mike Stephens held an online Q&A on 19th November, answering your questions about the various vaccines and their suitability for people with kidney disease.

### Key messages

- We expect the vaccine will be able to be used in all groups, including all renal patients, but this information hasn't yet been confirmed.
- The vaccines will only be recommended for widespread use if scientists and your healthcare team are confident they are safe to use for you, as a kidney patient.
- More information may be required from the manufacturers about the timing of the dose for dialysis patients to ensure it is not 'dialysed out'.
- The vaccine is an important tool but it's only part of the picture. Hand washing and social distancing remain vital in preventing the spread of infection.

Visit: <https://www.kidneywales.cymru/news/2020/11/23/dr-mike-stephens-covid-vaccineqa-full-report-session-recording/> to view the session and read the written Q&A.



## KIDNEY PATIENT CONFERENCE WALES

KEEPING WELL OVER WINTER

JOIN US VIA ZOOM FOR A VIRTUAL CONFERENCE  
WEDNESDAY 25TH NOVEMBER 2020  
FROM 6.00 TO 7.30 PM

## Learnings from patient conference

On 25 November 2020, a second virtual conference was held for people with kidney disease in Wales.

Chaired by Caron Jones, Renal Social Worker from Wrexham Maelor, the conference offered guidance from experts in psychology, exercise and diet on how to keep well over winter.

If you missed the conference, a recording can be viewed at LINK along with a written report.

The National Kidney Patient Reported Experience Measure

Online only this year

Your Voice Matters!

complete the survey at [kidneycareuk.org/prem-2020](https://kidneycareuk.org/prem-2020)  
1st October until 12th November 2020

Share your experience of kidney care

We need kidney care to always be improving and to do that it's important that we know how long with kidney disease, you have your say about your experience of care.

It's by listening to you and getting your feedback that we can make changes to improve services that really matter to you. This unit is committed to assisting you to take part in this important annual patient survey.

The online survey is available in English, Welsh, Urdu and Gujarati and is completely anonymous.

Don't have a phone or computer?  
Ask your renal team, family member, carer or friend if you can borrow a digital device to complete the PREM 2020.

"I was only too happy to fill in the PREM online as it was a lot easier!"  
Simon - Cornwall

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THE RENAL ASSOCIATION MEMBER SINCE 1979

Kidney Care UK

## PREMs

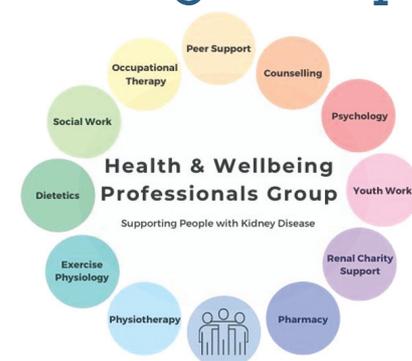
Thank you to everyone who took the time to complete this year's Patient Reported Experience Measure.

The feedback received from each and every one of you will be used to continue driving improvement to our renal service and will be available to read in 2021.

## Health and Wellbeing Group Winning Logo

You may remember we introduced you to members of the Health & Wellbeing Professionals Group in previous issues.

We are delighted to present the group's new logo, which illustrates the many members of the renal multi-disciplinary team who work together to support patients.



# Brexit...Your questions answered:

With the Brexit deadline looming rapidly, kidney patients may have questions or concerns about what this means for their treatment and care.

The UK officially left the European Union on 31 January 2020. A year-long 'Transition Period' followed, during which time no changes were made to the existing arrangements, allowing time to negotiate the final deal. The Transition Period ends on 31 December 2020, and at the point of writing, the outcome of negotiations between the UK Government and the EU is unknown.

The main concerns for kidney patients regarding Brexit include:

## Will my medication or treatment be affected?

Wales is part of UK wide arrangements for the supply of medicines, which are classed as 'Category 1' i.e. high priority goods. NHS Wales and Welsh Government have been planning for the end of the Transition Period and have mechanisms in place to manage any problems with supply, should they arise. We also have our own stockpile in Wales, which may be used if needed.

Kidney patients should not notice a difference to their care and treatment due to Brexit - if patients continue to order the same amount of supplies and avoid the temptation to over order or stockpile medication.

## Will I be able to have dialysis on holiday in the EU?

EU citizens have access to 'reciprocal healthcare arrangements'; this means that patients are able to access medical care free of charge via the European Health Insurance Card (EHIC). The EHIC care also covered holiday dialysis. If no deal is reached by 31 December, the benefits of



the EHIC card will end for UK citizens.

This means that holiday dialysis will no longer be covered, and dialysis patients would be required to pay for their treatment, at an estimated 1000 euros per week.

Sadly, as dialysis is a pre-existent health condition then this is not covered under medical insurance for going on holiday. Therefore, the reciprocal with EU and EHIC is so important.

At the time of writing, the outcome of the Brexit negotiations is unknown. However, we will keep you up dated with developments via this newsletter. **In the meantime, please speak to your healthcare team if you have any questions.**

# Checking in

Winter can be a difficult time for many people with the colder weather and darker nights, along with the stress of planning the perfect Christmas or strained family relationships.



Throw a pandemic and social distancing into the mix and it becomes a much more difficult experience. Be sure to check in with family, friends and neighbours and see how they're coping. Equally, don't be afraid to call someone if you're finding it hard yourself. Your phone call, text or video chat could be the interaction someone needs to lift their mood for the day. Some people will be spending Christmas alone this year, many of which going unnoticed as we all make our own festive plans.

Please reach out to those you think might be on their own, whether it be through bereavement, family living away, or those who are taking extra precautions with social distancing.

# Pregnancy Choices Study

The Wales Kidney Research Unit are undertaking an important UK wide study to learn more about women's experiences of kidney disease and decisions about having children.

If you are a woman aged 18-50 living with kidney disease we want to hear from you. It does not matter if you have children or decided not to have them your personal stories are important to help us learn.



Taking part involves completing an online survey. To hear more and take part please follow this online link. <https://cardiff.online-surveys.ac.uk/ckd-engage>



## Activity Calendar

The 2020 holidays will be very different for a lot of us.

Kidney Wales have put together a wellbeing activity calendar with something fun, informative, or creative for you to do every day of December.

Visit [kidneywales.cymru/kidney-wales-news/](https://kidneywales.cymru/kidney-wales-news/) for activity details and more.

## Collaboration with Lupus UK

On 2nd December, the three kidney charities held an information sharing webinar with Lupus UK, to increase awareness of CKD and lupus between the charities' employees and trustees.

Around a third of lupus patients will experience lupus nephritis in their lifetime, with a fifth of those requiring dialysis or transplant due to end stage renal failure. We all felt it important to broaden our knowledge of lupus and the support available from Lupus UK, so that we can better support those in the kidney community who are also affected by lupus.

If you would like to learn more about lupus visit <https://www.lupusuk.org.uk/>



# Eating and Moving Well over Winter

It can be difficult to stick to a renal diet when there are so many tempting foods and drinks around over the festive season.



Harriet Williams, Head of Dietetics at Betsi Cadwaladr UHB spoke at the recent patient conference on the positive food choices you can make, such as making your own mince pies using the Kidney Kitchen recipe. Check with your

renal dietitian if you're unsure about what foods you should be avoiding.

If one of your New Year's resolutions is to be more active, why not make an early start and try one of these exercises at home?

- **Kidney Beam:** Full of exercise videos and live classes for all abilities, this online resource is still available for kidney patients to use. Visit [www.beamfeelgood.com](http://www.beamfeelgood.com)
- **Keeping Me Well:** Created by Cardiff and Vale UHB, this website is aimed at people who have been less active during Covid-19. Whether you are recovering from covid, or have been less active due to shielding, there are exercise videos and advice for all abilities [www.keepingmewell.com](http://www.keepingmewell.com)

# Christmas availability

**Our charities' services will continue to run throughout most of December, so you can still access support from our advocacy teams, counsellors, peer mentors and information services.**



However, we will be taking a small break over the festive period to allow our staff to recharge for a new year of supporting Welsh kidney patients. We will each be taking a break on the following dates:

**Kidney Care UK:** Midday 24th December 2020, 9am 4th January 2021 (TBC)

**Kidney Wales:** Midday 24th December 2020, 9am 4th January 2021 (social media enquiries will be monitored)

**Paul Popham Fund:** 3pm 18th December 2020, 9am 4th January 2021 (Careline will be operating 10am - 4pm during 19th - 23rd, 27th to 29th December and 2nd to 3rd January)

We understand that Christmas can be a very difficult time for many and your situation doesn't stop just because our offices are closed. Here are some useful numbers if you need someone to talk to during this time:

**C.A.L.L.** (Community Advice and Listening Line) 0800 132 737 or text "Help" to 81066

**Samaritans:** 08457 90 90 90

**Childline:** 0800 1111

**Meic:** (For children and young people under 25, available in English or Welsh) 0808 80 23456 or text 84001

**Shout:** Text "Shout" to 85258

**Silverline:** (for people aged 55 and over) 0800 4 70 80 90

**DAN 24/7:** (The Wales Drug & Alcohol Helpline) 0808 808 2234 or text "DAN" to 81066

**Refuge:** (National Domestic Abuse Helpline) 0808 2000 247

## 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)

## Recipe of the Season!

When Christmas is so heavily focussed on food and drink it can be an incredibly difficult time for people with kidney disease. That's why Kidney Care UK have been working with the British Dietetic Association Renal Nutrition Group (RNG) to bring you a collection of recipes that the whole family will love this Christmas.



## Sausage Christmas Tree

### INGREDIENTS

- 2 x 320g packs of ready rolled puff pastry
- 340g of sausage meat
- 3-4 tablespoons of a chutney
- 1 egg yolk
- tablespoon of poppy seeds (optional)

## Gingerbread Christmas Log

Prep time: 20 mins Cook: 12 mins

Serves: 12

### INGREDIENTS

#### Christmas log

- 50g unsalted butter
- 50g treacle
- 50g golden syrup
- 2 balls stem ginger from a jar
- 2 tablespoons stem ginger syrup
- 4 large eggs
- 100g dark muscovado sugar
- 100g plain flour
- 1/2 teaspoon baking powder
- 2 teaspoons ground ginger
- Additional butter for greasing

#### Icing

- 200g unsalted butter, softened
- 250g icing sugar
- 2tsp vanilla extract
- 3 tablespoons stem ginger syrup

**With a little effort this is a festive showstopper! Full of the sweet festive flavours of ginger, cinnamon, and vanilla.**



For steps on how to make your Sausage Christmas Tree and Gingerbread Christmas Log as well as the full range of Christmas recipes go to:

[www.kidneycareuk.org/christmas-recipes](http://www.kidneycareuk.org/christmas-recipes)