

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.

The theme for this issue is Home Haemodialysis and its benefits during a pandemic, information about the button hole technique, the final summary of the Virtual Home Therapies Q&A and un-shielding as we come closer to the 16th August!

Are you distance aware?

From August 16th lockdown restrictions will be relaxed for all those who have been social distancing since March 2020.

Between now and then a **Distance Aware Shielding Badge** will be made available for you to wear when you start to head back out into the wider world. This is part of the **Distance Aware Campaign** to notify the general public that maintaining social distancing is everyone's responsibility going forward. While the general

public has made a very conscious effort to abide by the guidance, as with anything, fatigue sets in. This coupled with the increased anxiety of many around contracting the virus is where the ability to offer polite prompts has been welcomed in many settings.

The team producing the newsletter have ordered distance aware shielding badges that will be distributed with this newsletter. If you are reading this newsletter and have not had one and would like one please contact the team and we will endeavour to send one to you in the post.



For further information please contact the team.

Introduction to our home therapies teams across Wales

Since March of this year people living with kidney disease are identified as having increased risk of severe illness from COVID 19.

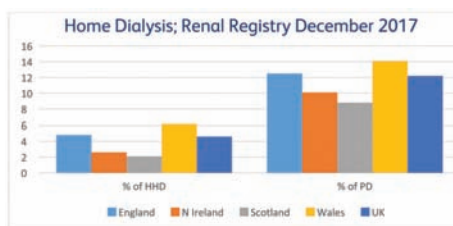


Renal teams have found themselves faced with challenges, constant adaptations and different ways of working. Data now shows that many of our dialysis population have been affected by this terrible illness. It is recognised that patients attending dialysis units have not been in a position to fully shield due to the need to travel.

For some people dialysing at home could be an alternative. It's not new, in fact it's been around for decades, long before the birth of unit dialysis! This mode of dialysis has come into its own during COVID 19, having treatment at home has kept patients well, safe and away from hospital backed by the Renal Association surveillance data. It is also well documented and recognised that home dialysis offers many advantages compared to unit/satellite dialysis:

- Longer life expectancy
- Improved quality of life
- Flexibility
- Ability to maintain employment if required (Walker et al 2018)
- Lower risk of infection (bacteria or virus) transmission.

In Wales, our vision is to ensure that all individuals with CKD are aware of the benefits of home dialysis. Even for those already receiving dialysis in a hospital/satellite, this option is still available to you too. Initially, all you need to do is have a conversation and explore the option of home dialysis with your doctor or nurse, you have nothing to lose by just asking the question! As you can see our HT teams across the country are friendly and motivated to support you!



Every year the renal registry produces a report. It's great to read that year on year Wales is well above the UK average for patients receiving home dialysis.

Over the last 12 months, excellent progress is being made in supporting patients to access home therapies. The % of patients in Wales receiving HHD has increased from 5.9% to 7.3% and a steady 12.4% for PD. In fact, in West



Wales, the team have reached an important milestone in June 2020, 50 patients + are receiving home haemodialysis with more patients training and planning to take their dialysis home.

When I ask nurses why you chose to work within home dialysis, this is the theme that been replicated across Wales.

- Reinforcing the benefits of home dialysis 'dialysis at home **fits around your life** and not the other way around where your life has to fit around dialysis...you are the boss and we teach you how to be safe!'



- Patients continue to tell us...**I feel I have got my life back** Hearing this phrase is one of the most enjoyable parts of our work. Being able to care, teach and support patients and their families gain independence and control of their life once again is an incredible feeling and really rewarding.



Button Hole Technique

Also known as "constant site" cannulation, the buttonhole technique is a less painful form of cannulation compared with other cannulation techniques. With the buttonhole technique, needles are inserted into the exact same place at the exact same angle during every dialysis session.

This leads to the creation of a tunnel into which, blunt tipped needles are inserted instead of sharp, pointed needles. The tunnel is formed by scar tissue, and is similar to the way tunnels are formed by scar tissue in the earlobes when you get your ears pierced.

The buttonhole technique can only be used by those who have an AV fistula. The walls of an AV fistula have muscle fibers that close after a needle is removed, which help prevent excess bleeding following each dialysis session. The term "buttonhole" refers to the two holes the needles create through your skin and into the AV fistula wall - both of which resemble actual buttonholes. With proper care and management, your buttonhole will result in less pain and discomfort during dialysis sessions and can serve as the permanent entry points into your dialysis access. The buttonhole technique can either be used by those who prefer to self-cannulate at home, or by those who prefer to self cannulate in a dialysis clinic or have needles inserted by a dialysis nurse.

What are the Pros and Cons of the Buttonhole Technique?

The buttonhole technique makes it easier for dialysis patients to perform selfcannulation, especially those who perform dialysis in the comfort of their own homes.

This cannulation technique is also found to be less painful than other techniques because the buttonhole technique allows patients to use a blunt needle. This technique is also often preferred by those who have a fear of sharp needles and who want to feel more comfortable performing self-cannulation.

One of the largest cons to the buttonhole technique is having to invest time in learning

how to properly self-cannulate if you decide to go this route. An experienced hemodialysis nurse will work with you on mastering this technique so you can do it yourself conveniently in the privacy of your home. Another potential downside associated with the buttonhole technique is the risk for infection at the buttonhole sites. However, taking proper care of your dialysis access can keep your buttonhole open and safe against infection for the lifespan of your dialysis treatment.

Fistula caps for dialysis patients

Vascular access is a phrase used to describe the surgical site on the body where blood flows from and returns to the body during haemodialysis (HD). A vascular access point may be an arteriovenous fistula (artery joined directly to a vein), arteriovenous graft (artery joined to vein using a plastic graft), or a central venous catheter (a line usually placed into the veins in the neck).

A fistula remains the first choice for HD access due to its longevity and reduced association with death and ill health, but nothing is perfect. Fistulas and grafts are essential in maintaining a kidney patient's life. However, it can often be challenging to maintain the function of a fistula or graft, and they frequently require regular intervention and/or surgery to ensure their survival. Read more on vascular access and the **'Put a Lid on It'** campaign on the Kidney Care UK website.

There are currently around 1,200 kidney patients on haemodialysis in Wales, with more than 900 doing so through an arteriovenous fistula (AVF) or an arteriovenous graft (AVG). However, these patients are at risk of life-threatening bleeds if their fistula or grafts fail.

Put a lid on it!

How to use your bottle top keyring in the event of a life-threatening bleed from your fistula or graft

Recognise!



Is your fistula bleeding?
Are you unable to stop the bleed?
Locate your bottle top keyring

Act!



Apply hollow side over bleeding site
Maintain pressure
Secure firmly with a bandage

Get help!



DIAL 999

Tell the emergency services you have uncontrolled bleeding from your dialysis fistula/graft

The simple rubber 'bottle cap keyring' launched by Kidney Wales in 2019 can be pressed over the bleed to stem the flow of blood, and buy the patient valuable time to dial 999 before they potentially bleed to death



Graham Evans, a patient from Mold Dialysis Unit said *"the life threatening bleed pack and information given to me at the dialysis unit give me peace of mind that if I was to bleed away from the unit, I have something that could help. I have the bottle top keyring attached to my keys."*

Renal Technical Services, RTS Morryston

The Renal Dialysis Technicians based at Morryston Hospital are responsible for all of the home haemodialysis and haemodialysis machine installations.



Simon Phillips, Andrew Long and Andy Cooper

The team cover the geographic area from Bridgend in the east to Pembroke in the west and as far north as Machynlleth.

The technicians carry out all of the planned maintenance and repairs on all of these machines, they are also responsible for the pre dialysis survey where patient's properties are checked to assess suitability for the installation of haemodialysis equipment and they then project manage these installations in patients' homes in readiness for the treatments to take place.

Placing a haemodialysis machine in the community is a complex process, where patient's houses need to be modified to accept the machine, permissions have to be sought from landlords, contractors have to be managed to ensure that all work complies to all the required safety standards, this is all carried out by RTS.

The job has many challenges but these can bring huge satisfaction it can range from programming machines with prescriptions and providing out of hours technical advice, to having to examine the depths of a cesspit to ensure that there is adequate drainage for a dialysis machine. But hopefully by placing and maintaining people home on dialysis it allows them to have greater control over their lives and their wellbeing.

A Patients View of the Button Hole Technique

Hayleigh Isaac, Support Services Co-ordinator for the Paul Popham Fund and Home Haemodialysis Patient shares her experience.

I have been on home haemodialysis for 9 years and throughout that time have needled myself using the buttonhole technique.

The thought of inserting your own dialysis needles can be quite scary, even when the needles are blunt.

I've had a huge needle phobia for as long as I can remember, so its fair to say I was terrified about starting dialysis and needling myself.

However, after learning about the buttonhole technique, having buttonholes created and giving it a go, my fears went away.

It's surprisingly easy to insert blunt needles, some people even describe it like putting a earring in.

It does take a little bit longer than sharp needles, as you need to 'wiggle' the needle into place rather than just pushing through the skin.

But once you learn the technique and get to know your fistula, it becomes second nature.



Using blunt buttonhole needles is also less painful than having sharp fistula needles, and there's less risk of blows.

Also, as it's gentler on your fistula, there's less risk of aneurysms (lumps) forming on the fistula.

As you can see from my picture, my fistula is still pretty small, even after needling it almost every day over the past 9 years.

My top tips for buttonhole needling are -

- Make sure you clean your arm thoroughly before needling to prevent infection
- Make sure you completely remove the scab before needling - use a magnifying light to help you
- Take your time - don't force the needle in
- Don't worry if you can't get the needle in first time - change the position of your arm or the direction/angle of the needle and try again

Give it a go - If I can do it, anyone can!

Un-Shielding...What is safe for me?

With the **16th August** approaching it is normal to feel worried about coming out of lockdown and what will be safe.

Whether you have been asked to shield or not, this question is very normal for you and for your family and friends who are not shielding. Being faced with an immediate and strange situation to shut yourself off from the world as we knew it from March 2020 until June 2020 initially, to then have that period extended to 16th August 2020 has potentially created a feeling of being 'institutionalised'.

It is normal to feel anxious about returning to the world after lockdown and to be concerned for your safety.

At a recent 'Post Transplant Kidney Café' patients shared their concerns with Dr Mike Stephens, - all attendees are currently shielding and had mixed views, some were ready to get back to normal and felt they had followed all the guidance and if they continued to follow the guidance they would be safe. Dr Mike Stephens could not have put it more reassuringly, as long as we are vigilant and continue to follow the guidance, wash our hands, don't touch our nose and mouth, stick to the safe distance and wear masks the risks were minimal.

A recent article in *The Guardian* Newspaper echoed this sentiment. It states it is normal for all, regardless of whether you are shielding or not to feel anxious about returning to the world after lockdown. Currently in Wales the end of shielding is set for the 16th August. For those feeling shaky about returning to the world after lockdown, it's worth breaking down the different factors and working out what you feel unsure about. If it's a trip to the supermarket, is it the time spent in the shop, or the drive? Could you walk instead? Could you have a socially distanced meeting with a friend to introduce a bit of familiarity? Ask: what would make this a bit more achievable?

It may be worth carrying out a personal risk assessment by following 5 simple steps:

- 1. IDENTIFY** what are the risks you may face when coming out of shielding? Going to the supermarket or back to work?
- 2. CONSIDER** how what could happen that would put you at harm? Carrying a shopping basket? Working alongside people and not being 2 metres apart?
- 3. FIND OUT** what is in place? Have the supermarkets got a process in place to prevent you from harm? Has your workplace got systems in place?
- 4. PLAN** put a plan in place to keep you safe, know what you will do when you get to the supermarket or work and follow it.
- 5. REVIEW** once you have been once review what it was like and what you need to do differently next time to keep you and everyone safe around you. The above steps will help to manage your expectations however If you are still feeling anxious or worried it is best not to ignore them.

- Try mindfulness-based practices. Anxiety and worry tend to be linked to things we're afraid may happen in the future. Being mindful can help to focus our attention on the present moment.

Catherine O'Leary Consultant Clinical Psychologist, Renal Services, University Hospital Cardiff and her team have also explored this topic. Catherine and the Renal Psychosocial Team discussed 'Managing Anxiety About Shielding & Going Out' which was recorded on youtube, you can copy this link into your internet browser to view the conversation.

<https://www.youtube.com/watch?v=yagNbkCoZGQ&feature=youtu.be>

You may not be worried for yourself or how you will manage coming out of shielding and maybe ready to get back out into the world and instead be worried about how others are keeping themselves safe or not.

In this case it is important that you take the precautions to help them keep you safe, by wearing a face mask when out and ensuring you follow the safe distance guidelines. As highlighted in this issue, Welsh Government and the NHS are issuing shielding badges through their 'Distance Aware' campaign.

These can be worn by those on the shielding list so that the general public are aware that you have been shielding and to be mindful of the Welsh Government and Public Health guidelines at all times.

Remember it is normal to feel anxious, follow the 5 simple assessments of the potential risks to evaluate how you will manage and ask for further guidance and help from your Renal Teams or the charities in Wales.

Here are the website links for the full articles from the guardian and bupa here:

<https://www.theguardian.com/lifeandstyle/2020/jun/26/im-anxious-aboutreturning-to-the-worldafter-lockdown-is-this-normal>
<https://www.bupa.co.uk/newsroom/ourviews/managing-anxietycovid19>

Bupa recently wrote an article on how to manage your worries coming out of shielding, that suggest. Rather than trying to fight the feelings, it can be helpful to take the opposite approach of noticing the feeling and accepting it. The following exercises may be helpful.

- Pause to take a few deep breaths. Then name the emotion you're feeling, accepting that it's present in this moment, but it will pass. You've most likely experienced these feelings before; reflect on past times you've felt anxious or worried and remind yourself they won't last.
- Write a list of the things on your mind. It can be helpful to organise the thoughts that go around your head and put them on paper. You might find that those thoughts feel less overwhelming in black and white compared to thinking about them in your head.
- Talk to someone you trust. Connect with family and friends via the phone or video calls. If you're feeling anxious or overwhelmed, talk to someone you find to be supportive. Call the Paul Popham Fund Careline and talk to a Peer Mentor who is also a person with kidney disease or carer who will understand

Home Therapies Case Study

The Paul Popham Fund held the first of their Patient Information Q&A Series in July which will be aired from the 4th August.

For further information and to view the Home Therapies Q&A: Explore and Give it a go! contact support@paulpophamfund.co.uk

Patient Story



Initially I was quite happy to be in shielding as like everyone else I had plenty to do and sort.

As time went on I could feel myself getting more anxious as I couldn't even go out for a walk or go to my sister's for food which was my normal routine.

I feel very lucky and fortunate to do nocturnal dialysis as it must be a worrying time going back and forth to hospital.

I was fortunate as I have neighbours that I could speak to in the garden at a distance, and my sister would call to do my shopping. I was feeling more depressed as time went on as I missed human company.

When the announcement came that if you were shielding you could go out for a walk, I felt so much better as I felt normal again.

Carer Story



My name is Pat and my husband Brian was on Automatic Peritoneal Dialysis (APD) at home.

Brian had been a type 1 Diabetic since he was a baby in 1939 and lived a full and healthy life until his late 50's. When it became apparent with his kidneys failing he would require dialysis we asked if he could have it at home.

With training and support this happened. Because of Brian's other health issues I became the one dealing with the whole process. I have to tell you I am useless with technology-mobile phones-computers etc. If I can do it anyone can. It is scary at first but the benefits are so great- soon everything becomes second nature. Your lifestyle doesn't revolve around frequent visits to the Dialysis unit in Hospital. You will feel so much better. Yes - Big changes-but people will be there for you on your journey.

As well as the professional people at your hospital there are organisations to give support and a listening ear.

I am a volunteer with the **Paul Popham Fund** - Renal Support Wales - and care so much that both kidney patients and their loved ones/carers get the most out of life the best way possible.

Dialysis Options and Choices

Why not pick a home therapy?

We have been undertaking research across Wales learning about the factors that influence patients and family members when making decisions about their future renal replacement therapy.

We especially wanted to learn about the barriers people face with choosing home therapies. One of the things we found was a lack of visibility of home dialysis - and as a result it is very difficult for people to imagine themselves on a home therapy, peoples first impressions of dialysis is almost always in a hospital. We want to start to change this so that people can more easily see themselves on home therapies, and recognise the benefits early. We have produced a webinar where you can share your thoughts and ideas about re designing training areas, and having spaces that 'show off' what dialysis at home looks like. Please follow this link to see more and tell us what you think.

https://www.youtube.com/channel/UCuMnTURP10rWTuKw9Y_eu-A

Managing stress and anxiety as we start to 'un-shield'

Facebook Live Q&A session, 5-6pm on 5 August 2020

The Coronavirus pandemic has added extra stress and strain to the lives of people with kidney disease, and their families, who are already dealing with the pressures of managing a chronic condition.

For those who are shielding, government guidance is that exercising and meeting people outdoors is encouraged, and it is possible to create an 'extended household' with another household. Understandably these changes may make you feel worried and anxious.

As we move towards the end of the current shielding period on **16 August**, Kidney Wales will host a Q&A with trainee Psychologist, Sina Gerhand, from Betsi Cadwaladr Health Board, who will answer your questions and concerns about stress and anxiety and will explain more about how to manage your stress bucket!

Please submit your questions in advance by 3 August to Danielle@kidneywales.cymru

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 these delicious, home baked scones.



Lemonade scones for proper cream tea:

INGREDIENTS

- 450g self-raising flour
- 250ml lemonade
- 250ml double cream

TO SERVE

- 480g clotted cream
- 240g jam



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/lemonade-scones-proper-cream-tea/>

Coming soon:

A reminder Welsh renal patients are shielding until the 16th of August.

In the next issue we will provide an update on holiday dialysis and will soon feature a live Q&A session with a date TBC. We know this is a really important topic for you. It is also very complex and it is really important that we approach this in a way that is safe for everybody across the UK. We are working hard to achieve this and will update you as soon as we have a robust national plan in place to keep everybody safe.'

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

T: 02920 343940

E: team@kidneywales.cymru

Team from Paul Popham Fund

T: 01792 654182

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The Post Transplant Café

Next meeting is on **Friday 14th August from 11.30am to 1.00pm**

The Theme for this month is: **Coping Strategies During Shielding and Un-Shielding**

To receive the link for this meeting please contact Hayleigh Isaac: support@paulpophamfund.co.uk