

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 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 introducing you to your multi-disciplinary teams, transitioning and why it is OK, un-shielding and sign posting to helpful services. If you are feeling anxious or worried about returning to 'normal' please reach out as soon as possible.

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

Please enjoy this edition!



Renal Multi-Disciplinary Teams

What is a Multi Disciplinary Team (MDT):

In renal services the MDT includes specialist workers, such as dieticians, social workers, physiotherapists, psychologists, youth workers, counsellors and occupational therapists.

They all work together with Doctors and Nurses to help you manage your kidney health and social care needs.

The teams bring together the expertise and skills of different professionals to assess, plan and manage care jointly.

An MDT is vital to your overall care and support. We will be introducing you to all the wide variety and various members of the MDT across Wales in future issues - with a 'meet your MDT' feature. Here we feature two members of the MDT a psychologist and social worker. All of the MDT are important to patients health and wellbeing but this group in particular can support your mental health needs - especially as we begin to un-shield and connect with a new normal.



Clinical Psychology

Hello, my name is **Kate Shakespeare**, I am a clinical psychologist and I work in Ysbyty Glan Clwyd Renal unit in north Wales. I am part of a larger team of clinical psychologists, and have worked for the last 5 years across the three units in north Wales. The main part of my role is to offer psychological support and therapy for people with renal conditions and their carers or spouses.

Therapeutic work may focus on adapting to living with and managing day to day with a long term health condition, making decisions about treatments or procedures, or in some cases

working through frightening or traumatic experiences.

I normally see people in the renal centres; however, since COVID-19 I have been offering telephone or video sessions. This has been really challenging at times for some people who much prefer face to face appointments, for others they've felt reassured that they don't need to come into hospital. I am also involved in delivering training to members of the MDT and supervise Trainee Clinical Psychologists and I am involved in collaborative research aimed at improving services for people affected by kidney disease.



Renal Social Worker:

Hi, I'm **Jayne Davis**, I work in Ysbyty Glan Clwyd, North Wales. I'm one of a team of dedicated Renal Social Workers from across Wales.

Renal social workers support patients and their families through the journey of renal disease, from early diagnosis, pre dialysis, dialysis, transplant to end of life care and bereavement support for families. We work closely with the multi-disciplinary team especially the specialist nurses. We offer emotional support, an opportunity for people to talk through their feelings and experiences of treatment and therapy, to help them live better with it. Chronic illness can also have a huge impact financially on people, we therefore support people with housing matters, benefit support, and access a variety of grants to help people improve their quality of life. Covid-19 crisis changed how we worked, home visits were stopped and we increased our support by telephone, email and skype. We saw an increase in people needing support with benefit and

employment issues, accessing food boxes and community/volunteer support especially for those who were shielding, we have also been supporting a great number of people who were very anxious and frightened by the pandemic. We receive referrals from all MDT members, but more recently have seen an increase in self referrals (directly from patients), which is heartening as people must be aware of who we are and how we can help. If you have a cause of concern or a query we might be able to help with, please ask your renal team to refer or contact us directly.

Patients experience of MDT support

"I'm very grateful that [my Consultant] Dr Mike Stephens could see what I thought I'd hidden so well, and referred me to Psychologist, Dr Catherine O'Leary. I was broken and very fragile when I met her. Life in general and kidney disease had taken its toll. She enabled me to work on my mental wellbeing. Without her, my body may have been fixed but my mind would still have been broken. A real holistic approach."

Kate Dunsford



"I honestly don't know, how I can truly explain or show my gratitude towards my renal social worker, Caron Jones. Your professionalism is exemplary, keeping to boundaries yet always exuding the rapport of a true friend with a heart of gold. Thank you seems so insignificant for the effort and work you have put in over the 15 years and more. That is an achievement in which I count myself extremely lucky. From bottom of my heart I wanted to say Thanks for being the amazing you". Your job means to us patients that we are not just a case number.

Chris Simpson



Have you heard of the Health & Wellbeing Professionals Group?

In 2019 we established the All Wales Health and Wellbeing Professionals Group to represent all of the multi-disciplinary team involved in the care of renal patients in Wales.

The Group offers a singular voice that contributes to service improvements, policy making and most importantly for you good quality renal care.

Who are the members of the H&WPRG:

In addition to the renal MDT this group has representatives from kidney research and kidney charities in Wales.



Clinical Exercise Physiologist:

My name is Jamie Macdonald. I am a clinical exercise physiologist working in the School of Sport, Health and Exercise Sciences at

Bangor University. I am part of the Wales Kidney Research Unit and I collaborate with the MDT Teams working in the renal units of Betsi Cadwaladr University Health Board. I coordinate a research program and an applied service for patients. This program and service both aim to enhance quality of life of patients throughout the stages of chronic kidney disease. Our interventions focus on lifestyle factors such as increasing physical activity. We typically have other scientists, PhD students, Masters students, undergraduate students, physiotherapists, and clinical research fellows (Foundation Year Two

and Specialist Registrar Doctors) to support delivery of these research studies and applied interventions. Part of my work is to coordinate with Welsh (Welsh Renal Clinical Network Health and Wellbeing Professionals Group), UK (UK Kidney Research Council Special Interest Group Physical Health and Mental Wellbeing Group) and international (Global Renal Exercise Group) groups to ensure findings from research on physical activity has impact upon care of patients with chronic kidney disease."

To find out more, share you views and see opportunities to take part in research please visit our website.

<http://www.kidneyresearchunit.wales/impact-case-studies>



Jo, Paul Popham Fund:

Jo runs the Paul Popham Fund which aims to provide all people with kidney disease in Wales with a better quality of life by providing services and

projects that improves their knowledge and their emotional, physical, and financial wellbeing. The charity runs the Peer Support Service which trains people with kidney disease and carers and family

members to become Volunteer Peer Mentors who provide information and support on living as a kidney patient. Alongside the Peer Mentor Service the charity runs a Counselling Service, a series of Kidney Café's where patients meet others in an informal setting to discuss topics and listen to guest speakers, welfare grants and a Buddy Service where patient can access support with shopping. Jo reports to a board of Trustees, is supported daily by Hayleigh Isaac, Support Service Co-ordinator who runs the Peer Support Service, Hayley Evans who supports the charity with all administration and develops other projects and Lynne Kirkham the Clinical Psychologist and is also supported by the Steering Group for the Peer Support Service to help in its maintenance and development. The charity joined the Health and Wellbeing Group after producing a report on the psycho-social support patients said they needed.

The Health and Wellbeing Group logo competition:

As this group is new we are hosting a competition for the groups logo or brand.

The Chair, Caron Jones (renal social worker from Wrexham, North Wales), is also part of the working group who produces and distributes this newsletter. So it's time to get creative and send in your ideas to the contact details below! The winning logo will be displayed here and form part of the brand of the All Wales Health and Wellbeing Professionals Group.

Thinking of a Holiday?

We all recognise the immense benefit of a holiday for everybody. However please remember that people receiving dialysis and those with transplants, are highly vulnerable if they sustain a COVID-19 infection.

Leading national kidney organisations have come together to provide guidance for Dialysis Away From Base (DAFB). You can read the published guidance here https://renal.org/wp-content/uploads/2020/07/DAFB_Final.pdf

The key messages remain that if you are planning any type of holiday please consult with your clinical care team FIRST - they will have the most up to date information and will work with you to see what DAFB is possible.



'Flare ups' as we come out of lockdown are likely. You will be aware that lockdown measures have been re imposed in certain areas in England which have had huge impact on peoples holiday plans. DAFB is therefore very complex, there is no 'one size fits all' solution. However you can help by talking to your clinical care team and working with them to come up with a plan, that gives you and your family a break but also keeps you safe.

The guidance will be kept under review and updated as soon as new information becomes available. Insurance coverage for cancelled trips can be found on the Associate of British Insurers website <https://www.abi.org.uk/products-and-issues/topics-and-issues/coronavirus-hub/>

If you have had an overseas holiday cancelled or normally travel overseas for a holiday consider a staycation. Wales has some of the most beautiful coastline and rural landscapes in the world. Please talk to your team about any holiday plans.



Income Maximisation

Did you know that being a home therapies patient may entitle you to a reduction in Council Tax?

For more tips on how to boost your income visit <http://www.kidneycareuk.org/income-maximisation/> or contact any of our charities for support."



Lowering the Shield

Shielding will be paused from Sunday 16th August.

Everyday of this week the Chief Medical Officer for Wales will be answering important questions and sharing advice to help people prepare.

Visit the Welsh Government website, twitter @CMOWales or Facebook to hear responses and view top tips.

Switching treatment...

Do I have choice...YES YOU DO:

Moving onto different treatments is an intrinsic process in the life of a patient with kidney disease and should be planned and anticipated when possible.



A single therapy option might not be adequate across a patient's entire lifespan and many patients will require a switch in their treatment modality to adapt the treatment to their clinical and psychosocial needs.

There are several reasons why a patient might change their treatment modality including:

- Previous modality failure, such as peritoneal dialysis (PD) failure or kidney graft failure
- Unplanned dialysis start: patients with no pre-dialysis education who have not been informed about dialysis choices or patients who had an acute unplanned dialysis start and did not have the opportunity to initiate treatment in their chosen modality might wish to consider a different therapy option that better fits their lifestyle
- Patients who have a change in lifestyle or social circumstances who wish to reconsider their initial modality choice
- Medical situations that require a change in dialysis modality, such as peritonitis, vascular access problems or haemodynamic intolerance, or that require more frequent treatment prescriptions
- Cessation of dialysis treatment to be replaced by kidney transplantation.
- A patient's decision to withdraw altogether from dialysis treatment.

Depending on their specific circumstances, patients can switch between different Renal Replacement Therapy (RRT) options, namely kidney transplantation, PD, unit based haemodialysis and home haemodialysis (HHD), or opt for conservative management.

Managing Stress and Anxiety

Techniques to help patients manage stress and anxiety as we 'un-**shield**.

Sina Gerhand, Trainee Clinical Psychologist from Betsi Cadwaladr Health Board, hosted a live Q&A session on 5 August to answer questions from patients and provide practical advice to help to manage stress and anxiety.

Her top tips include adopting a stress bucket exercise, identifying values, baby steps, remember to breathe, managing uncertainty, healing after

The outcomes of each should be evaluated, considering short-term as well as long-term benefits and risks. In most cases, the need for a change in RRT option is predictable, thus providing an opportunity to pre-emptively prepare the patient, the family and the health care team, given that a planned transition has been associated with better patient outcomes compared with an unplanned change. It is important to highlight that transition to another therapy option should not be considered as a 'failure' of treatment, but rather as an 'expected progression' in the patient's treatment options. Transition should be considered as a 'gradual move' from one therapy option to another.

It is well recognized that early kidney transplantation is the best RRT option for many patients with end-stage renal disease (ESRD). However, most patients will need to spend some time on dialysis prior to transplantation or when a transplant fails. Time on the transplant waiting list can be variable. This implies that transition between dialysis modalities will be a reality for the majority of patients, especially those who face a long wait for transplantation or those for whom a kidney transplant is not possible.

Everybody is unique and everybody will have their own story about this journey, good and bad! We would like to hear yours. Please get in touch via the contact details below or you may feel more comfortable speaking to your healthcare team and they can then relay the messages to us. We will use the stories to help others who are making decisions about renal replacement therapy, people who are moving onto a different treatment, and to improve the overall service.

loss of connections.

You can view her top tips in detail here, <https://www.kidneywales.cymru/news/2020/08/10/9072/>.

Remember to reach out if you are feeling overwhelmed or anxious and do it as soon as possible to avoid escalation.



The National Kidney Federation

The National Kidney Federation (NKF) is a UK wide kidney charity run by kidney patients for kidney patients.

The NKF has two main areas of focus, campaigning for improvements to renal provision and treatment, and national patient support services.

Our current national focus sees Andrea Brown, Chief Executive and Mark Davis, Liaison Officer and kidney transplant patient involved in several workstreams run by the Renal Association, the British Renal Society and KQUIP - all of these are concerned with COVID-19. We have an unshielding group as this issue is very important for all within the renal community going forward.



The NKF is made up currently of 51 Kidney Patient Associations (KPA's) from all across the UK, which in essence make up the controlling council of the NKF. Mark Davis, Liaison Officer provides support to the KPA's and every year there is an AGM / KPA day which is free to attend and is well attended by KPA members. In addition the NKF holds a national conference / patient event usually in October, but this year sadly postponed due to COVID).

From the start of the pandemic we have seen an unprecedented rise in calls and emails to the helpline, from anxious and concerned patients and carers. The free to call national kidney patient's telephone helpline is available Monday to Friday 9am to 5pm. This is manned by Pauline and Stephen - Freephone number 0800 169 09 36. On average the helpline receives around 150 to 200 calls per week.

As well as offering the helpline, the NKF distributes a 24 page magazine entitled "Kidney Life" 4 times per year free of charge. We also provide over 120 free of charge patient information leaflets, which are written by medical professionals and are regularly reviewed to ensure they remain up to date. Copies of "Kidney Life" and the patient leaflets are available on our informative and up-to-date website www.kidney.org.uk

We keep in touch with all our supporters by emailing every month the "In Touch" electronic newsletter to over 5,000 patients who have kindly supplied us with their email addresses.

Our social media links are:

Facebook

<https://www.facebook.com/KidneyNKF/>

Twitter https://twitter.com/NKF_UK

We hope this gives you a snapshot of what we offer and do for kidney patients. Please don't hesitate to contact us if you would like to be involved or are seeking advice.

Virtual Patient Conference

On Wednesday the 2nd of September 5pm-6pm we are hosting the first virtual All Wales Kidney Patient conference.



KIDNEY PATIENT CONFERENCE WALES

Covid-19: THE NEW NORM FOR KIDNEY PATIENTS

JOIN US VIA ZOOM FOR A VIRTUAL CONFERENCE **WEDNESDAY 2ND SEPTEMBER 2020** BETWEEN 5.00 AND 6.00PM

THE CONFERENCE IS FREE TO ATTEND AND IS OPEN TO ALL PEOPLE WITH **KIDNEY DISEASE** ACROSS WALES. The aim is to provide advice and guidance to kidney patients in light of the Covid-19 pandemic as well as responding to questions as a result of the recent Kidney Care UK 'Worried Sick' survey.

Guest speakers will include:
Fiona Loud - Director of Policy Kidney Care UK
Mike Stephens - Consultant Transplant Surgeon at the University Hospital of Wales

For more information about guest speakers and to book your free place visit: kidneypatientconference.wales

Contact: EMAIL: info@kidneypatientconference.wales TEL: 07960 182525



CYNHADLEDD I GLEIFION ARENNOL CYMRU

Covid-19: Y NORM NEWYDD I GLEIFION ARENNOL

YMUHWICH A NI DRWY ZOOM AM GYNHADLEDD RITHWIR AGORED I BOB UN A CHLEFYD ARENNOL AR DRAWS CYMRU. Covid-19 yn ogystal ag ateb cwestiynau a ganiatodiad i arolwg ddiweddar Kidney Care UK 'Worried Sick'.

Ymhlith y siaradwyr gwaddd bydd:
Fiona Loud - Cyfarwyddwr Polisi Kidney Care UK
Mike Stephens - Llywodraethwr Trawsblannu Ymgynghorol yn Ysbyty Athrofaol Cymru

Yn fwy o wybodaeth am ein siaradwyr gwaddd ac i archebu eich lle am ddim, ychydig i: kidneypatientconference.wales

Ychydig i: info@kidneypatientconference.wales FF: 07960 182525

The theme is COVID 19: A NEW NORMAL. The specially coordinated conference will provide the latest advice and guidance and respond to questions arising from the recent Kidney Care UK - Worried Sick survey.

To register and book your free place visit kidneypatientconference.wales or email info@kidneypatientconference.wales

If you would like to attend but cannot get online for ANY REASON please get in touch through the details below or tell your kidney care team - we can support with this.



Kidney Matters magazine

Issue 10 of Kidney Care UK, Kidney Matters magazine is now out!

Kidney Matters is a free quarterly magazine for everyone affected by kidney disease. Get your copy here <https://www.kidneycareuk.org/about-kidney-health/kidney-matters/>

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 delicious, fruity mousse.



Raspberry and passion fruit mousse:

- INGREDIENTS**
- 4 passion fruits, pulp only (approx 150g)
 - 300g fresh, or frozen raspberries
 - 2 leaves gelatine (vegetarian alternatives possible)
 - 3 egg yolks
 - 3 egg whites
 - 100g caster sugar
 - 300ml fresh double cream, softly whipped
 - 2 tablespoons of water



A smooth mousse with a delicious fruity flavour. Unfortunately we do not recommend this recipe for transplant recipients or those on immune-suppressant medication as the eggs are not thoroughly cooked. Visit the link below on Kidney Care UK for the method and more delicious recipes. www.kidneykitchen.org

Liz Baker Excellence in Renal Nursing Award 2020

NOW OPEN for nominations
 Closing date: 4th September 2020

Is there an individual that goes the extra mile, successfully implemented a project or initiative to improve patient care?



Rhwytwaith Clinigol Arennol Cymru
 Welsh Renal Clinical Network

Please email your nominations to: gail.williams4@wales.nhs.uk

Are you #distanceaware

The Distance Aware initiative was launched in Wales with the support of Welsh Government to enable individuals and organisations to self-identify as wanting others to maintain distance where possible.

It has seen an overwhelmingly positive response with nationwide interest and endorsement. The initiative is now backed by the Department for Health and Social Care and Her Majesty's Government.

This simple symbol to prompt distancing, and take forward the #DistanceAware initiative, consists of a double ended arrow on a shield background.



Get in touch if you would like any badges. Please visit the website here for further details <https://www.kidneywales.cymru/news/2020/08/04/social-distancing-matters-now-ever-distanceaware/>

Coming soon: Returning to 'normal' guide for your mental health and wellbeing.

Digital technologies, who is excluded and how can we help.

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
 E: enquiries@paulpophamfund.co.uk