

Kidney patient Covid-19 update

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Welcome to the first edition of a newsletter for kidney patients in Wales to provide the latest information and advice during this unprecedented time.

It has been compiled by Kidney Care UK, Kidney Wales, Paul Popham Fund, Renal Support Wales and the Welsh Renal Clinical Network, which oversees services for adult kidney patients in Wales.

It includes information on services and activities available to support people with kidney disease through this difficult time. A lot of information and support is available on the internet, and we have included references to where specific information can be found.

If you do not use the internet, please ask a family member or friend to help you, or phone one of our friendly teams, who will help you to find the information you need.

FOR INFORMATION & SUPPORT

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How can people with kidney disease protect themselves against Coronavirus (COVID-19)?

The UK Government advises the whole population to practice social distancing.

Some people face increased risk of severe illness from coronavirus (COVID-19) and need to be particularly stringent in following social distancing measures.

This includes people with chronic kidney disease and those who are on dialysis, unless they have been advised to shield.

This includes transplant patients, those who are over 70, and people with specific types of kidney disease and who take certain medication, and dialysis patients who have been contacted by the NHS and advised to shield.

People who are extremely vulnerable to coronavirus due to an existing health condition will receive a letter from Wales' Chief Medical Officer.

They will be advised to follow the shielding guidance, which means staying at home for 12 weeks and taking other sensible measures.

The advice to stay at home for 12 weeks means you will need support from others to get food and medicines.

Are you shielding and not able to work?



If you are shielding on medical advice and are unable to work, you may be placed on furlough leave by your employer and the government will pay up to 80% of your salary while you are not able to work.

Note that public sector employees are exempt from the scheme. See further information: [gov.uk/guidance/claim-for-wage-costs-through-the-coronavirus-job-retention-scheme](https://www.gov.uk/guidance/claim-for-wage-costs-through-the-coronavirus-job-retention-scheme)

Free Food Boxes

From **31 March**, if you have been advised to adopt shielding measures, you will be able to request a weekly food box.

Each free box will provide essential food for one person for a week, and will be delivered weekly. If more than one person in your household is shielding, they will also receive food. If you do not have anybody who can help then contact your local authority.

You should first try to get help from: family members, friends or other people in your community, carers or community organisations and voluntary organisations.

See further information: [gov.wales/get-coronavirussupport-extremely-vulnerable-person](https://www.gov.wales/get-coronavirussupport-extremely-vulnerable-person)





Please don't hesitate and ask your nursing team for more information.

I am a dialysis patient, do I need to shield?

The categories of patients deemed to be at high risk have been agreed at a UK-wide level following expert advice and a letter has been sent by the NHS to these patients to set out what measures they need to take in order to shield.

People with severe single organ disease, including kidney failure, who have spent time in intensive care during the last three years, have already been sent a letter to advise them to shield.

If you are a dialysis patient who has NOT spent time in intensive care in the last three years, and your consultant feels that you need to shield, they will ask your GP to arrange for a letter to be sent to you from the NHS to explain what you need to do.

If you have received a letter from the NHS advising you to shield on medical grounds, you will be able to access additional support, including a free food box, from your local authority and supermarkets.

I have dialysis at my unit, how does Coronavirus affect my treatment?

Attend dialysis at your unit as normal, unless advised otherwise. Ensure your dialysis unit has your current telephone number and address. When you are in your own home, follow the Welsh Government guidance; stay home.

Save Lives. Protect the NHS. Practice good hand hygiene practice at home by washing your hands for 20 seconds. On your dialysis days wash your hands before you leave your home and before you enter the dialysis unit and vice versa.

How will Coronavirus affect patient transport?

Non-Emergency Patient Transport Service (NEPTS) will continue.

For all dialysis patients who do not have any symptoms of Covid-19, NEPTS are introducing a range of measures to enable patients to be separated from each other as much as possible.

Ambulance Vehicle (wheelchair or stretcher)

A maximum of 2 patients will be travelling when a double crew is supporting. A maximum of 3 patients will be travelling when a single crew is supporting.

Car based Vehicle/Taxi/ Voluntary Car Scheme

A max of 1 patient will be travelling in each. It has also been decided that no escorts will be accepted on the booking unless they are clinically essential to ensure the well-being of the patient or a parent/guardian accompanying a child.

What is the dialysis transport reimbursement scheme?

The transport reimbursement scheme is available for all patients who were in receipt of transport to attend unit haemodialysis from the Welsh Ambulance, Non-Emergency Transport Service (NEPTS) from 15th March 2020. Payments of 38p per mile will be made for travel from your home to the dialysis unit and home again from the date your application to the scheme is accepted. This scheme has been provided as a way to enable patients, friends and family, where they can, to support the efforts of the Welsh Ambulance Service to continue to provide essential services at this difficult time. The scheme will be kept under constant review so it can be adapted as necessary to ensure that all dialysis patients in Wales can receive their dialysis safely.

Patients say that there are many advantages, some including more time spent at home, also travel time to and from the dialysis unit is reduced as other patients are not being picked up or dropped off on route. Approximately 130 patients have enrolled for this scheme so far

For those who do not wish to join or are unable to join, please be reassured that transport will still be provided by NEPTS. However be prepared, there may be delays as the pressure on service increases.

What measures are being taken to keep dialysis patients safe?

Key workers (NEPTS and dialysis unit staff) protecting all (patients and staff) within the service and have introduced TRIAGE into the pathway during the pandemic. This is a process of sorting out people based on their needs.

Patients with no symptoms of COVID 19:

Travel to your dialysis unit as normal. In line with new national guidance, issued on 2nd April 2020 your NEPTS staff may ask you to wear a face mask for the duration of travel to and from the dialysis unit, please be re-assured this is for your own protection and for the safety of others (patients and staff) who use the service.

For patients who feel they may have symptoms of COVID 19: On or before the day you are due to attend for dialysis, inform your dialysis unit before you leave your home. The dialysis unit nursing team will arrange for a COVID 19 diagnostic swab to be taken, this may be arranged at your home or at your dialysis unit. Your team will make sure you can still access your dialysis treatment and will advise you about any necessary precautions or changes to session time. Your transport (if required) will be also arranged although it might be different vehicle or run that you would normally have.

How can I help?

You will be aware from the news and social media that the situation around COVID 19 changes on a daily bases, which has an impact on our everyday lives and also to the NHS. Key workers (NEPTS and dialysis unit staff) will be made aware of any service updates or changes as necessary.

Please follow their instructions and guidance; they are there to help and support. Help your nursing team by participating in Share/Self-care; give it a try, many people enjoy the experience of learning new skills, nurses enjoy teaching, you'll be fully supported.

Above all, be patient with key staff, they are working hard to support and protect you during the COVID 19 crisis.

Kidney Care UK have produced very helpful Coronavirus guidance for people with kidney disease, which helps kidney patients to understand what measures to take to protect themselves.

It is available on the Kidney Care UK website:

www.kidneycareuk.org/news-and-campaigns/coronavirusadvice/

Paul Popham Fund, Renal Support Wales provides a Careline service for Kidney Patients in Wales

0800 038 8989

This telephone service enables patients and families to call and talk to someone who understands their circumstances, who can provide reassurance, answer basic questions, find out answers to specific questions, signpost to local services and offer support during the Coronavirus outbreak. Patients and their family can access this service between 9:00am to 6:00pm 7 days a week. The Careline is manned by the charity's Befriending (Peer Mentor) Team, who are kidney patients, carers or family members who have been trained to become volunteers for the charity.

List of local online support groups

Home Therapies Kidney Café

[facebook.com/groups/hometherapieskidneycafe/](https://www.facebook.com/groups/hometherapieskidneycafe/)

This is a support group for patients undergoing any type of home dialysis therapy. During this unprecedented time the group can be accessed on-line.

To join the group and gain support from your peers type the address into your internet browser, or go to facebook, search 'home therapies kidney café' and ask to join the group.

Llynfi Valley Kidney Café

[facebook.com/group/llynfi-valley-kidney-cafe/](https://www.facebook.com/group/llynfi-valley-kidney-cafe/)

Support group for all kidney patients living in the Llynfi Valley area. During this unprecedented time the group can be accessed on-line.

To join the group and gain support from your peers type the address into your internet browser, or go to facebook, search 'Llynfi Valley Kidney Café' and ask to join the group.

They have firsthand knowledge of what patients are going through and can offer advice, information, support or even simply a friendly voice to chat to during this difficult time.

As a country we have all been advised to self-isolate as much as possible to help protect us from the virus. This is particularly important for kidney patients who have been asked to self-isolate for 12 weeks. These are potentially difficult times for many kidney patients, especially those living alone who may not have anyone to share their concerns with. Others may just want to have a chat about updates from Public Health Wales, their local health board, local council, Welsh Government or something they have heard they may want clarity on. Hopefully, this initiative will help kidney patients to manage some of the challenges arising from the Coronavirus outbreak.

Walk for Health group

[facebook.com/groups/ppfwalkforhealth/](https://www.facebook.com/groups/ppfwalkforhealth/)

A walking group for kidney patients of all abilities. The walk leader is a kidney patient and has designed the walks to be suitable for all patients who would like to join. Walks are currently suspended but normally take place once a month.

To share walking routes or chat to like minded people, type the above address into your internet browser or go to facebook and search for 'PPF Walk For Health' and ask to join the group.

Kidney Café Parent's & Carer's Group

[facebook.com/groups/kidneycafeparentsandcarers/](https://www.facebook.com/groups/kidneycafeparentsandcarers/)

Support group for parent's and carer's of children with kidney disease. The group can be accessed on-line.

To join the group and gain support from your peers type the address into your internet browser, or go to facebook, search 'kidney café parents and carers' and ask to join the group.

Our Careline is available 9:00am-6:00pm 7 days a week. If patients, carers or family members would like to chat to a Befriending (Peer Mentor) outside of these hours or would like the volunteer to call them at a pre-arranged time or If you would like to receive a regular telephone call from us, please call **0800 038 8989** or email support@paulpophamfund.co.uk to organise this. You can register free of charge - please ensure you include the following information in your email. This will help us deal with your registration more efficiently.

- Name - Address - Telephone no.

Please let us know if you're are a: **kidney patient, carer or family member**

- An emergency contact - who do you want us to contact in an emergency?

- Password - our staff member will say your chosen password at the start of every call. This is to give you peace of mind so you know you're speaking to an Paul Popham Fund Peer Mentor.



Transplant Café

[facebook.com/groups/SouthWalesKidneyTransplantCafe/](https://www.facebook.com/groups/SouthWalesKidneyTransplantCafe/)

Support group for transplant patients. (This is named 'South Wales Transplant Café' due to the face-to-face meetings taking place in South Wales, but North Wales patients are welcome to join the group and contribute). The group can be accessed on-line.

To join the group and gain support from your peers type the address into your internet browser, or go to facebook, search 'South Wales Kidney Transplant Café' and ask to join the group.

We understand that this is a particularly difficult time for people with kidney disease and their families. We are taking calls daily to talk through how the virus is affecting our lives in many ways.

Our Patient Advocates, Brett Dowds and Shaun Ruck, are available to answer questions or simply to have a chat.

Please give us a ring on **02920 343940** or drop Shaun or Brett an email:

Shaun@kidneywales.cymru
Brett@kidneywales.cymru

Financial Assistance

Kidney Wales has grants available to provide financial assistance to patients who are most in need.

Grants can cover things such as household bills, household items and travel costs. Each of the grants must be applied for with the support of the patient's Kidney team, this could be a Social Worker or part of their clinical team.

It is important that all requests for Grants are supported by members of this team as they will also be aware of additional funding



Kidney Wales works with young adults aged 16-30 with kidney disease through the *Can Do Youth Project*.

Search for '**Can Do Youth Project**' on Facebook or contact Shaun Ruck (South Wales) or Brett Dowds (North Wales) for a chat via Facebook or on **02920 343940**.



We recently had a live Q&A session with Dr Mike Stephens, Consultant Transplant Surgeon. We have sessions coming up on managing mental health, welfare and benefits, diet and exercise, as well as fun posts such as a quiz and a weekly 'Live Lunch', hosted by our Patient Advocate Shaun, will talk with the group about what they're eating for lunch, and share ideas and questions. It's a great way to connect with other patients and families - please join us! Search for '**Kidney Wales Community**' on Facebook.

Look out for some delicious kidney friendly recipes in the next issue!

