

Kidney patient Covid 19 update



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Uned Ymchwil Arennol Cymru
Wales Kidney Research Unit



Welcome to the latest edition of this newsletter, where we will focus on the Covid 19 Vaccine that many of us will be receiving over the coming weeks and months..

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

We hope you enjoy reading this edition!

COVID 19: all you need to know about the virus and the vaccine

Covid 19 is caused by a new coronavirus, known as SARS-Cov-2. It was first identified in late 2019. It is very infectious and can lead to severe respiratory disease.

Many people who are infected may not have any symptoms or only have mild symptoms. These commonly start with cough, fever, headache and loss of taste or smell.

Some people will feel very tired, have aching muscles, sore throat, diarrhoea and vomiting, fever and confusion. A small number of people then go on to have severe disease which may require hospitalisation or admission to intensive care.



Remember!

Covid 19 is spread through droplets breathed out from the nose or mouth, particularly when speaking or coughing. It can also be picked up by touching your eyes, nose and mouth after contact with contaminated objects and surfaces.

There is no cure for Covid 19 although some newly tested treatments do help to reduce the risk of complications.

You will also no doubt have heard about vaccines for Covid 19 in recent weeks.

The purpose of this update is to give you as a kidney patient up to date information about;

1. What the vaccine is
2. What it does
3. Answer your most frequently asked questions and
4. Sign post you to trusted sources of further information and wider support.

Key messages in this newsletter:

1. The vaccine is safe. Your kidney care team and the Welsh Renal Clinical Network strongly advise you to have the vaccine when offered.
2. When you are called for a vaccine you should make it a priority to attend - if you have any concerns or questions speak to your kidney care team.
3. The biggest defence for you against Covid 19 is still to maintain the golden rules, HANDS, FACE, SPACE

What is a vaccine?

A vaccine is a medicine given to people to help protect you getting sick from known diseases. Vaccines work with your immune system. Your immune system is the name given to the complex network of cells, tissues and organs that stops you becoming very sick or unwell. A vaccine simply helps your immune system to fight off known diseases.

Is getting Covid19 really as bad as they say?

Covid 19, the condition caused by Coronavirus (also known as SARS COV2) is the biggest health emergency in living memory. It is a global pandemic. Nearly 2 million people have died across the world and many more have been left with serious health complications. Very sadly many more will die before the pandemic ends. The NHS has never faced a challenge of this scale before.

In Wales people are continuing to get infected, and once the virus starts to spread as it is now, it can do so rapidly. Even if you, your family or friends haven't experienced it first hand, that doesn't mean it isn't a threat. Sadly, the learning from the first wave of the pandemic is that people with significant kidney disease such as those on dialysis, those with kidney transplants and those in the advanced kidney care clinic (also called the low clearance clinic) are at high risk of becoming very sick if they contract Covid 19.



Being vaccinated will help to protect you and reduce the spread of this deadly virus. The vaccine is proven to reduce the severity of symptoms and is the best way to protect you against Covid 19 as well as following the HANDS, FACE SPACE messages.

Why are Vaccines Important?

Vaccines are safe, effective and save lives.

Vaccines teach your immune system how to protect you from diseases. It's much safer for your immune system to learn this through vaccination than by catching the diseases and attempting to treat them.

Vaccines can reduce or even eradicate some diseases, if enough people are vaccinated. Since vaccines were introduced, diseases like smallpox and polio that used to kill or disable millions of people are gone from the UK. This has been achieved through mass vaccination programmes, which build protection amongst the whole population. This is why it is important to vaccinate as many people as possible.

The vaccine will be provided free through the NHS. It may take a while to get to everybody who is eligible, but, when you are invited, make sure you get yours.

Most people have said they would get a Covid 19 vaccine when it's available, including HM The Queen!

Reality check

This is the biggest vaccination programme ever attempted. Nothing like this has even been imagined before let alone operationalised by our NHS. It is therefore unlikely that everything will go exactly 'to plan'. The best thing you can do to make this work and help the teams who are working hard to implement the vaccine programme and take us out of the pandemic is to attend your vaccination appointment(s) when called and stick to the government guidelines, HANDS, SPACE, FACE.

Does the vaccine stop me getting Covid 19?

The vaccine is likely to stop you becoming very sick or seriously unwell and needing hospital treatment. It will not stop you catching Covid 19 and importantly spreading Covid 19 to others. A vaccine is not a silver bullet, it will only work effectively alongside additional preventative measures, that is, everybody who is called for the vaccine takes it, and maintaining the golden rules, HANDS, SPACE, FACE. Wash your hands frequently, stay at least 2 metres apart from people, avoid touching your face and wear a face covering whenever you are near people who are not in your 'bubble'. Covid 19 cases are still increasing, you are most likely to catch it from somebody you know. Having the vaccine when called and keeping to the social distancing rules is the best way to keep you and your loved ones safe.



"The impact of Covid 19 has been heart breaking for people with kidney disease and for those who care for them. Now we have hope for brighter times ahead with a safe and effective vaccine."

I'm fortunate to have been vaccinated myself and privileged to have given it to people with kidney disease. I look forward to the day all our friends and colleagues across our kidney community have theirs."

Why should I agree to the vaccine?

Sadly, the learning from the first wave of the pandemic is that people with significant kidney disease such as those on dialysis, those with kidney transplants and those in the advanced kidney care clinic (also called the low clearance clinic) are at high risk of becoming very sick if they contract Covid 19.

It is your choice whether you have the vaccine but your kidney team would strongly recommend that you do as this will protect you.

All of the vaccines that have been rolled out in the UK are suitable for kidney patients (whether transplant, dialysis or other kidney conditions) and should be taken, based on advice from your kidney doctor or GP; some people with kidney disease have already received their vaccines.

The vaccines for Covid 19 have been rushed through, how do I know it is safe?

For a vaccine to reach the general public it will have to work and be safe.

It is true that vaccine research takes time but it's all the steps beforehand, like getting funding and getting approved that really takes up the majority of the time. What has sped up in the development of a Covid 19 vaccine is the direct availability of the funding from the UK Governments which has given the scientist the opportunity to start the research as soon as Covid19 emerged.

The Medicines and Healthcare Products Regulatory Agency (MHRA) and Medicines Research Authority have also sped up the process of approval as all staff time has been focussed on this one vaccine - things like administrative

paperwork that used to take months is now being done in days. This is what's brought down the time for delivery of the clinical trials.

It has also been helped by new technology, including the ability to rapidly manufacture vaccines. And supply - the vaccine started to be produced so that as soon as it was known to be safe and effective it could be made available.

How do I know the vaccine will protect me from Covid 19? What do all these percentages of 'efficacy' mean?

The first vaccine, (Pfizer BioNTech) to be approved by the MHRA was tested in a clinical trial of over 40,000 adults and the second vaccine (Oxford Astra Zeneca) was tested in over 20,000 adults.

Efficacy just means effectiveness in providing the desired outcome. A simple way to think about this is; if the vaccine had a 100% efficacy that would mean for every 100 people vaccinated all (100%) would be protected from catching Covid19 or suffering severe disease requiring hospital care. If the vaccine had 70% efficacy, for every 100 people, 70 would be protected from catching Covid19 or suffering severe disease.

You might have heard different percentages of effectiveness given to each of the vaccines described in the news, but due to all the differences in the groups of volunteers in the clinical trial, there is no ability to directly compare them. All vaccines approved in the UK have been shown to be to be safe and have a very high level of efficacy.

What about all these new treatments for Covid19? Doesn't that make it less scary if I get infected?

There are some treatments that have been proven to make a difference, for example the antiviral drug Remdesivir can reduce the length of illness if your doctors feel it is safe to give to you. Two steroid drugs, dexamethasone and hydrocortisone, have been shown to save lives but only in people who are seriously ill in hospital.

A vaccine can help stop you getting sick from it in the first instance, and lessen the impact of the disease on you and the NHS.

Why do I need to wait to be called to get the vaccine?

To help protect those who need it the most, the vaccine is being offered to groups at highest risk first. As more vaccine becomes available, it will be offered to other people.

The Joint Committee for Vaccination and Immunisation (JCVI) has made recommendations for the provisional prioritisation for Covid 19 vaccines. Wales and other UK administrations will be guided by the recommendations. The committee strongly agrees that a simple age-based programme will likely result in faster delivery to those at the highest risk.

This priority list is as follows:

1. Residents in a care home for older adults and their carers
2. All those 80 years of age and over and frontline health and social care workers
3. All those 75 years of age and over
4. All those 70 years of age and over and clinically extremely vulnerable individuals.

This includes people who have received a transplant, on dialysis or have been diagnosed with CKD5

5. All those 65 years of age and over
6. All individuals aged 16 years to 64 years with underlying health conditions which put them at higher risk of serious disease and mortality
7. All those 60 years of age and over
8. All those 55 years of age and over
9. All those 50 years of age and over

Welsh Government has given a commitment to offering the vaccine to everyone in the top 4 groups by mid-February 2021. This means all people in Wales over the age of 70 and the clinically extremely vulnerable. This includes people who have received a transplant, on dialysis or have been diagnosed with CKD5.

All people over the age of 50 and everyone who is at risk be because they have an underlying health condition, which includes anyone with kidney disease CKD1-4 will be offered the vaccination by the spring.

This will mean that people in priority groups 5-9 will be vaccinated in the order of priority by the spring. At the same time as priority group 6 i.e. those aged 16-64 years with long term health conditions the vaccine will be offered to:

- those who are the main carer of an elderly or disabled person whose welfare may be at risk if the carer falls ill
- younger adults in long stay nursing and residential settings, and staff

What about the staff in the dialysis units and clinics? Are they getting the vaccine? How do I know the staff are being checked?

All front line NHS staff are getting the vaccine as they are in a top priority group.

Front line just means anyone who is caring for or supporting patients. This includes all the doctors, nurses, pharmacists, dieticians and care staff who look after patients in dialysis units and at face to face clinics.

The Welsh Government recognises the importance of keeping staff safe so they can carry on looking after patients. As well as the vaccine, front line NHS staff are going to be offered a test twice a week to check if they have Covid19. This is because it is known that people can have Covid19 without experiencing any symptoms. If they test positive, they need to self-isolate as even though they don't have symptoms, they can still pass the virus on.

Why has the roll out of the vaccine changed? I thought I needed two jabs within a few weeks to protect me?

The latest evidence suggests the first dose of current Covid 19 vaccines provide high levels of short-term protection. As a result the Joint Committee on Vaccination and Immunisation (JCVI) has advised that the interval between the first and second dose should be up to 12 weeks. This allows as many people as possible to be protected with a first dose when the level of protection is at its highest.

While there is some protection gained from the first dose the second dose is required to provide

effective protection and to ensure the protection lasts longer.

Response to the vaccine can be seen from around 14 days after the first dose.

The second dose will further improve this and make the response last longer.

It is important that you still attend for your second vaccine when called as this will ensure your protection lasts longer.

Can I choose which vaccine I get?

There is no evidence that one vaccine is better than another for kidney patients or people on immunosuppressants. It would be best to take the first vaccine that is available in your area, to avoid any delays in protecting yourself.

I am on dialysis, will the vaccine be dialysed out?

No. Kidney care teams routinely provide hepatitis B and seasonal influenza vaccine to dialysis patients. The Covid19 vaccine is no different and can be safely given when you are on the unit. Having the vaccine will significantly reduce your risk of harm if you come into contact with the virus.

I have had a kidney transplant. Is the vaccine safe for me?

There is no evidence that the vaccines themselves could cause infection in patients who are on immunosuppressive drugs for a kidney transplant or some types of kidney disease.

There is no evidence that the vaccine would lead to rejection of a kidney transplant or will cause any harm to your kidneys.

The key message is both vaccines were effective in all groups in the trials and will therefore protect you.

I am on the waiting list for a transplant, should I have the vaccine?

Yes, you are at high risk of suffering severe harm if you come into contact with the virus. The virus is circulating at very high levels in Wales, so you should have the vaccine when offered. The vaccines are considered safe for organ transplant recipients and people on the transplant waiting list. Your transplant team will be happy to advise you further if you are concerned.

I am on the transplant waiting list. Will I need to be suspended from the transplant list for a period of time after receiving the vaccine?

No, you will not need to be suspended from the waiting list. Response to the vaccine starts around 2 weeks after the first dose and improves significantly after the second dose.

If I have the vaccine, will I need to have Covid 19 test if I am admitted to hospital for a transplant?

Yes. The vaccine is given to prevent severe Covid 19, so infection could still occur and result in no symptoms or very mild symptoms. Your kidney care team will arrange for your test as a precaution to make sure you are absolutely safe to have your transplant.

Should I still have the flu vaccine?

Yes, all people with kidney disease should have the flu vaccine when offered.



"I did have some anxiety about having the COVID vaccine, but I read the facts and made the decision that is right for me. I miss my friends and family and being able to enjoy life to the full, having the vaccine is the best way to help me to live the life I want to."

Brett, home dialysis patient and Patient Information & Support Manager at Kidney Wales

Current advice is to separate flu and Covid 19 vaccinations by at least one week.

I am clinically extremely vulnerable, will other members of my household be able to receive the vaccine at the same time as me?

The Joint Committee on Vaccination and Immunisation (JCVI) have said that there is not enough data yet about how the vaccine can reduce transmission (passing the virus from one person to another), so the committee cannot recommend that families are vaccinated together. The Committee are continually monitoring how well the vaccines are protecting the clinically extremely vulnerable as well as the wider population and may change their advice as the vaccine programme is rolled out.

It is important that family members attend for their vaccine when called and everyone continues to follow COVID-19 guidance, such as social distancing, hand hygiene and use of face masks.

Are there any side-effects from having the vaccine that I need to know about?

Like all medicines, vaccines can cause side effects. Most of these are mild and short-term, and not everyone gets them.

Anaphylaxis (a severe allergic reaction) can happen after vaccines or medicines and health professionals are trained to watch out for the early signs and initiate prompt treatment. All vaccination staff will have access to anaphylaxis recovery kits. The vast majority of people will not be at risk of anaphylaxis after being administered a Covid 19 vaccine, and the benefits in preventing the serious complications of Covid 19 for most people outweigh the risks.

Since the immunisation campaign commenced on Tuesday 8 December, there have only been 2 reports of anaphylaxis shortly after receiving the Pfizer BioNTech Covid 19 vaccine. The individuals were treated promptly and have recovered.

As a precaution, you will be asked if you have ever had any serious allergic reactions before you are offered vaccination.

Can I get Covid19 from the vaccine?

No the vaccines do not contain living organisms, and so are safe for people with disorders of the immune system.

It is therefore also suitable to use in those who are immunosuppressed, although they may not receive the same level of protection (efficacy) as the general population. It is still very important that all people with Chronic Kidney Disease (CKD) who are immunosuppressed or are taking immunosuppressant medication have the vaccine.

It is possible to have caught Covid 19 and not realise you have the symptoms until after your vaccination appointment.

The most important symptoms of Covid 19 are recent onset of any of the following:

- a new continuous cough
- a high temperature
- a loss of, or change in, your normal sense of taste or smell
- some people also have a sore throat, headache, nasal congestion, diarrhoea, nausea and vomiting

If you have any of the symptoms above, stay at home and arrange to have a test. Don't worry information about how to reschedule your vaccine appointment will be provided in your letter of invitation. Attending a clinic for a vaccine if you think you have Covid 19 only puts others at risk - it will not protect you if you already have Covid 19 and are experiencing symptoms

If you are receiving dialysis inform your kidney care team as soon as possible. They will be able to make arrangements for you to receive your dialysis in the safest way possible to protect you, other patients and staff.

If you need more information on symptoms visit 111.wales.nhs.uk

What about the new variant of the Covid19 virus? Will the vaccine protect me from it?

There is no evidence to suggest that the vaccines approved for use in the UK will not work against this variant. This will be monitored closely.

I have had Covid19 already, do I still need the vaccine?

You should get vaccinated. We do not yet know the length of immune response in those who've had the virus. There is no evidence of any safety concerns from vaccinating individuals who have previous tested positive for Covid 19 or have a history of experiencing symptoms.

If you have had a positive Covid 19 test your health professional may ask you to wait for up to 30 days before having the Covid 19 vaccine.

I have been told I will get my vaccine tomorrow, but I don't feel well. Should I still go?

If you currently have any symptoms of Covid 19 or a positive test for Covid19 please let your kidney care team know. If you are on dialysis, they will help you to make sure you can travel to have your dialysis safely and all people they will discuss with you the best time to rearrange to have your vaccine. It is usual practice, with any vaccine, to wait for recovery from an acute infection or illness, but your kidney care team will be able to talk to you about what is best for you.

If I have the vaccine or have had Covid 19 can I still infect other people?

The Joint Committee on Vaccination and Immunisation (JCVI) have said that there is not enough data yet about how the vaccine can reduce transmission.

Transmission means passing the virus from one person to another.

This is why it is important that everyone continues to follow COVID-19 guidance, such as social distancing, hand hygiene and face masks even if they have been vaccinated or have had Covid19.

If I get the vaccine, will I be immune for life?

Duration of protection from the vaccine remains unknown, and further doses may be necessary in the future. For this reason, it is essential that we continue to follow the 'hands, face, space' guidance.

Like all medicines, no vaccine is 100 per cent effective. Some people may get Covid 19 despite having the vaccination, but their infection will be less severe.

People who have received a transplant, on dialysis or have been diagnosed with CKD5 are considered clinically extremely vulnerable to Covid 19, and were previously advised to shield. This is because their immune system is suppressed by disease or treatment they are receiving so they cannot fight infection well. It also means they do not respond as well to vaccines as the general population.

However, it is expected that the vaccines will provide protection against severe disease. This is very important as kidney patients are at high risk to poor outcomes if they become infected with Covid 19.

Studies are planned to assess the response of kidney patients to vaccination and to identify whether revaccination is required (as with flu vaccination).

Until it is known how long the vaccine can protect people it is important that everyone continues to follow COVID-19 guidance, such as social distancing, hand hygiene and face masks even if they have been vaccinated.

I am pregnant or planning on having children, will the vaccine affect the baby or my future planning?

The Joint Committee on Vaccination and Immunisation (the JCVI) confirms that although the available data do not indicate any safety concern or harm to pregnancy, there is insufficient evidence to recommend routine use of Covid 19 vaccines during pregnancy.

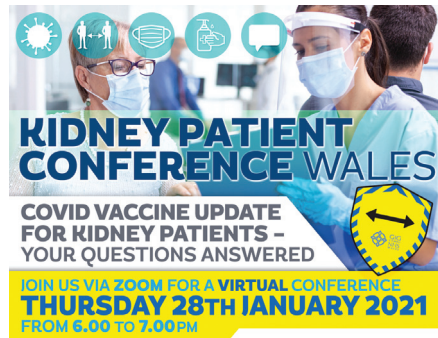
However, the JCVI now advises that if a pregnant woman meets the definition of being clinically extremely vulnerable, then she should discuss the options of Covid 19 vaccination with her obstetrician and/or doctor. This is because their underlying condition may put them at very high risk of experiencing serious complications of Covid 19.

The most likely relevant groups of pregnant women are:

- **Solid organ transplant** recipients
- Those with severe respiratory conditions including cystic fibrosis and severe asthma
- Those who have homozygous sickle cell disease
- Those receiving **immunosuppression** therapies sufficient to significantly increase risk of infection
- Those receiving **dialysis** or with **chronic kidney disease** (stage 5)
- Those with significant congenital or acquired heart disease

The best advice if you are pregnant or planning a pregnancy is to speak to your kidney care team about the vaccine.

Patient Conference



Join us via Zoom for a free 'VIRTUAL' conference on **Thursday 28 January 2021** between **6.00 and 7.00pm** entitled the **Covid 19 Vaccine Update for Kidney Patients - Your Questions Answered**. Open to all people and their families living with kidney disease and health professionals in Wales.

Guest speakers are **Susan Spence**, Renal Clinical Network Manager, Welsh Health Specialised Services Committee and **Chris Brown**, National Pharmacy Lead for Welsh Renal Clinical Network

To find out more information and to book please visit the website:

<http://kidneypatientconference.wales/> and send any questions in advance by email to info@kidneypatientconference.wales

Comments about the vaccine from patients:

"I had my vaccine yesterday as I work in a residential home and to be honest I was quite relieved and excited as being a transplant patient I am quite vulnerable to this virus. The booking system was easy and the staff at the test centre were efficient, friendly and everything was fully explained. This made feel at ease and knowing all my questions were answered, my main concern was receiving the injection in my fistula arm but the staff in my renal unit and those in the vaccination centre explained it was perfectly fine. After getting the jab I was asked to wait for 15 minutes and given a leaflet to read regarding the vaccine. The whole thing was quite frankly a breeze and although I am still fully aware that all guidelines regarding hand washing and social distancing must still be adhered to, I feel a much safer now and quite excited to think that pretty soon life shall return to some kind of normality. Everyone should go and get the vaccine when offered."

Louise, Bangor Transplant Patient

"I'm looking forward to having the vaccine as it will hopefully help protect me and my family, as well as other people.

It will also mean that I can get back to work and regain some sort of normal where I can hug my mum and feel comfortable being able to go out with my children.

Both my partner and my mum have had their first doses as they are both nurses, and I'm hoping I won't have to wait much longer to receive mine."

Joseph Townsend,
Kidney Transplant Recipient

Where can I get more information?

The best source of information is from your Renal Care Team. They are kept up to date with all the vaccine developments and they know your personal health situation best!

Please avoid reading social media messages if it's not from an official trusted source such as Public Health Wales, the NHS or the Kidney Charities. There is so much information that is wrong and causing a lot of unnecessary fear and stress.

Mis or inaccurate information causes harm. The World Health Organisation has produced a handy guideline for what you can do to stop this. As with everything it starts with our own behaviours. Have a read and see how you can help 'flatten the infodemic curve'.

<https://www.who.int/emergencies/diseases/novelcoronavirus-2019/advice-for-public/myth-busters>

If you want to look at some trusted sources the following are the most up to date sites:

Kidney Care UK Covid 19 guidance for patients with kidney disease:

<https://www.kidneycareuk.org/coronavirus>

Renal Association FAQs for kidney patients on the Covid 19 vaccine:

<https://renal.org/sites/renal.org/files/Patient%E2%80%99s%20Frequently%20Asked%20Questions%20letter%20on%20COVID-19%20Vaccines%20z%20December%202020.pdf>

Renal Association Briefing document on key messages on the Covid 19 vaccine:

https://renal.org/sites/renal.org/files/Briefing_document_on_COVID_19_vaccination_in_renal_community%2024%20December%202020.pdf

Covid 19 vaccination for adult patients with kidney disease: a position statement from the UK renal community:

<https://renal.org/healthprofessionals/covid-19-ra-resources/covid-19-vaccination-adult-patients-kidneydisease>

British Transplant Society position statement on Covid 19 vaccination in Solid Organ Transplant Recipients:

<https://bts.org.uk/wpcontent/uploads/2020/12/December-2020-BTS-position-statement-vaccinationin-solid-organ-transplant-recipients-FINAL-002.pdf>

British Association of Paediatric Nephrology advice for children and young people with kidney disease:

<https://twitter.com/BAPNephrology/status/1346946085105905666/photo/1>

For information & support

Team from Kidney Care UK

Head Office: 01420 541424

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Team from Kidney Wales

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