

FREQUENTLY ASKED QUESTIONS ABOUT CORONAVIRUS (COVID-19) and NEUROLOGICAL DISEASE

UPDATED Jan 11 2021

What is Coronavirus?

Coronavirus disease 2019 (COVID-19) is a new illness that can affect your lungs and breathing. While most people with COVID-19 develop mild or uncomplicated illness, people with some neurological conditions are at higher risk of becoming very unwell.

Coronavirus is spread in sneeze or cough droplets. To infect somebody, the virus has to get from an infected person's nose or mouth into the eyes, nose or mouth of another person.

What are the symptoms?

The main symptoms to look out for are:

- a new cough
- shortness of breath
- muscle pain
- Fatigue /tiredness
- Fever equal to or above 38° /Chills
- Reduced smell / test

How do people get coronavirus?

You have to have been in close contact with somebody who has been affected . Given that COVID19 is highly prevalent within the community, we must assume that all close contact are potentially COVID carriers.

What can I do to protect myself?

People with chronic neurological conditions are considered by the HSE as a “vulnerable” group.

<https://www2.hse.ie/conditions/coronavirus/at-risk-groups.html>

The HSE Level 5 guidelines include for Vulnerable Groups include the following

- **Stay at home**
- **You should not allow any visitors to enter your house**
- Do not shake hands or hug people, even your family
- Do not touch your face with your hands
- Make a joint plan with family, friends and neighbours on what to do if you become ill.
- If you need to stay in touch with friends and family, use social media
- If you don't usually use social ask a family member to show you how to do this

What happens if somebody in my family gets COVID-19?

They should follow the advice of the HSE, and isolate themselves.

You should not be in the same room as them.

They should use a different bathroom, cooking implements, dishes and cutlery.

All surfaces in the house should be wiped down regularly with disinfectant.

Clothes other items belonging to the infected person should be placed in a plastic bag, and washed at high temperatures.

What happens if I get COVID-19?

It is very important to following the HSE advice about social isolation to protect you from getting coronavirus.

If you do develop symptoms, you should first call your GP / the HSE helpline to arrange testing.

You should assume you have the virus until the test come back negative.

If your test is positive, you should rest at home, socially isolate in accordance with the HSE guidelines, and take paracetamol.

Most people get better.

What about my out patient appointments? I have not heard anything from the hospital. Will these be cancelled?

The Neurology teams continue to have lists of all appointments.

They will provide remote clinics by telephone / video link where appropriate.

These calls will take place during regular clinic hours.

You will receive a call from the clinic secretary to ask whether you would prefer a phone consultation of (if possible) a video call.

I am worried that if my family gets sick they won't be able to take care of me

This is a very understandable concern. The HSE is putting services in place to help people. Where necessary, your Neurology team will work with the HSE to make sure that you receive care, even if the normal caregivers are temporarily out of action.

I am a carer of somebody with a neurological disability. What should I do?

- Follow the HSE guidelines about social isolation
- Take regular exercise within 5km from home
- Wash your hands frequently
- Wash down surfaces in your living space frequently
- Do not shake hands or hug people
- Do not touch your face with your hands
- No visitors.
- Make a joint plan with family, friends and neighbours on what to do if you become ill.
- If you think your loved one has developed symptoms of COVID you should call your GP. The GP will decide if testing is required.

What happens if I have outside carers? Do these increase my risks?

- Carers have been educated about spreading COVID-19, and will reduce their risks
- They will not come if they think that they are likely to give you the virus.
- They may wear a mask when they visit you. Do not be alarmed about this.

I have heard the children are invisible carriers. What should I do about children visiting?

- Schools have been closed now to stop children spreading the virus
- Follow the HSE guidelines about visiting
- If you have children, they should not have playdates, or visit playgrounds.
- Children should be taught to wash their hands regularly

VACCINATION

Ireland is currently rolling out a vaccination programme using Pfizer-BioNTech vaccine, with plans for addition Moderna and Astra-Zeneca vaccines in the coming weeks to months.

How are vaccinations prioritized?

The prioritization for who gets vaccinated first has been done by an expert team within the HSE, details can be found here.

<https://www.higa.ie/reports-and-publications/health-technology-assessment/extremely-medically-vulnerable-groups-respect>

People with chronic neurological illnesses are prioritized as “vulnerable patients”. There is a case to be made for some groups to come within the “extremely vulnerable category”, (for example, those who already have problems with breathing and who need to use assisted ventilation) and the Neurology Advisors are working with the HSE to advocate in this regard.

As the vaccines are approved and supplies arrive the vaccination programme will gather pace, and we expect that all vulnerable groups will be offered vaccination within the coming 3-4 months.

Should I accept the Vaccine?

Based on what we know about the way these vaccines work, and high quality evidence from studies of other vaccines, we do not think that vaccine will make any neurological symptoms worse.

What are the Risks?

The vaccines available in Ireland have been fully tested, and the risks are very low. Some people feel slightly unwell for a few days afterwards but recover. The usual risks around vaccination (allergic reactions, etc) also apply. But in general there have been no major problems.

You might read materials on social media about risks of vaccinations. Be careful about the sources, as many of these sites are not based on any scientific information.

The risks of falling ill and spreading COVID, and the risks of dying from COVID19 are much higher than the risks of any harm that the vaccine might do.

Vaccinations for People with Neurological Conditions who are on Treatments that Affects the Immune System

The COVID-19 vaccine might be less effective for people that have recently taken or are taking certain treatments that affect the immune system. Some treatments for neurological disease might reduce the effectiveness of any vaccine, if they prevent the immune system from mounting a complete immune response to the vaccine

If you are on such a treatment (for example, Multiple Sclerosis treatments) **we do not advise that you stop**, because the potential harm would outweigh the potential benefit. For this reason, your doctor is likely to advise you to get vaccinated while on treatment. This is because even a reduced response is likely to be better than none.

MS Ireland have provided detailed information on treatments and how they may impact on the effectiveness of COVID-19 vaccines:

Ocrelizumab (Ocrevus) and Fingolimod (Gilenya)

Ocrevus works by depleting B cells. B cells produce antibodies which provide immunity against vaccines. Those receiving Ocrevus have a reduced ability to respond to vaccines at all times. For this reason, it is thought that being on this treatment may mean that a COVID-19 vaccine will not be as effective as it could be. It may reduce the response to some vaccines by up to 50%.

For those just starting this treatment, it may be beneficial to delay the first dose in order to receive the vaccine first.

For those already on this treatment, delaying further infusions would have a limited benefit for increasing the effectiveness of a vaccine.

It would still be advisable to receive a COVID-19 vaccine.

Advice for those on Rituximab would be similar.

There may also be a reduced response for those taking Fingolimod (Gilenya). It would not be advisable to stop treatment in order to increase immune response to the vaccine.

Alemtuzumab (Lemtrada) and Cladribine (Mavenclad)

Recent treatment with Alemtuzumab (Lemtrada) may reduce response to a vaccine. It is recommended that those who receive this treatment wait 3 months after their treatment to receive a vaccination.

There may be a reduced response to a vaccine with Cladribine (Mavenclad) and it may be advisable to wait 3 months after a course before receiving a vaccine.

Please note: Second courses of Lemtrada or Mavenclad can safely be delayed for several months without concerns for a return of disease activity. This will allow some flexibility to schedule vaccination in advance.

Delays to start treatment

If starting for the first time on any of the above treatments (Ocrevus, Gilenya, Lemtrada and Mavenclad) you should discuss with your team whether it might be preferable to wait until you have been vaccinated. The risks of this strategy will depend on your individual case and on the availability of the vaccine.

Other Treatments for Multiple Sclerosis (Copaxone, Aubagio, Tecfidera, Avonex, Extavia, Plegridy, Rebif, Tysabri)

There is no reason to believe other treatments will reduce the efficacy of vaccines. This covers: glatiramer acetate (Copaxone), teriflunomide (Aubagio) , dimethyl fumarate (Tecfidera), beta interferons (Avonex, Betaferon, Extavia, Plegridy, Rebif), and natalizumab (Tysabri).

Haematopoietic stem cell transplantation (HSCT)

You should wait at least 6 months after treatment before getting vaccinated as HSCT will likely reduce response to the vaccine.

Other important points

The current vaccines require 2 doses and for some treatments (for example Ocrevus, Mavenclad, or Lemtrada) your MS team may advise you on specific timing in relation to this. For example, it may be advisable to wait until after your second dose of vaccine before a further course of DMT – or to resume treatment after a single dose of vaccine (delaying the second).

You should leave at least a 7-day gap between getting the flu vaccine and a COVID-19 vaccination.

SUMMARY

Until we know more about the vaccine, everyone with a chronic neurological condition should continue to follow government advice to reduce the risk of catching and transmitting COVID-19 even if they have received a vaccine for COVID-19.

People that are on the clinically extremely vulnerable list should continue to take extra precautions to protect themselves from catching the virus.

Even if you are vaccinated, it takes some time after vaccination to achieve immunity, so it is crucial to maintain precautions after initial vaccination. It takes up to 28 days after the first dose of the Pfizer-BioNTech vaccine and up to 22 days for the Oxford-AstraZeneca vaccine to get some level of immunity. For both vaccines, the best response is achieved with two doses and you should receive the second booster dose when offered, but there is significant protection from a single dose.

Everyone's risk is different and will depend on individual circumstances. You should have an opportunity to discuss the right choice for you with your Neurology team.