

# FREQUENTLY ASKED QUESTIONS ABOUT CORONAVIRUS (COVID-19) AND MND 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 MND 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
- Loss of taste /smell

## How do people get coronavirus?

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

## How can I tell I have coronavirus if I also have MND?.

Some of the symptoms of COVID-19 might seem similar to those of MND – e.g. shortness of breath. But these symptoms have to cluster together, along with a temperature, to make us suspect that this is COVID19

## What can I do to protect myself?

**People with MND are classed as a “vulnerable” group.**

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

The HSE Level 5 guidelines 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
- If you need help, the MND team can provide people who can talk this through with you.

### **What should I do if my Riluzole prescription runs out?**

You can call your IMNDA or Beaumont nurse, and they will arrange a prescription or an e-prescription that will be sent directly to your pharmacy.

### **What should I do if I cannot contact my GP?**

If your problem is MND related, you can call your MND nurse, and they will advise. If needed, they will contact the Medical team and arrange a phone call / virtual call / clinic visit / home visit as needed.

### **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 and 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 follow the HSE advice about social isolation to protect you from getting coronavirus.

If you do develop symptoms, you should first call your GP to arrange testing.

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

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

### **Please let us know if you have tested positive and we will give you additional telephone advice.**

Most people get better.

### **HSE guidelines for the carers if the patient is positive:**

If you are caring for someone who cannot self-isolate, you and the rest of the household should restrict your movements for 17 days. Do this from when they first developed symptoms or when they tested positive, if they did not have symptoms.

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

The MND teams in Beaumont, Cork and Galway continue to have lists of all appointments for the MND clinics.

They will provide remote clinics by telephone / video link for all MND patients as needed.

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 or (if possible) a video call.

If you do not receive one of these calls and you have a clinic appointment, you can contact your IMNDA nurse directly and she can organize a telephone call with a team member.

This will usually take place on the date of your outpatient appointment.

You can also call your IMNDA nurse/Hospital Specialist Nurse if you would like an emergency appointment with the clinic.

Multidisciplinary team members including Physiotherapy, Occupational Therapy, Speech and Language Therapy and Dietetics will provide advice, assessment and management by phone or video on request from the doctors and nurses.

### **I am using Non invasive ventilation (NIPPY). What happens if I get COVID-19?**

If you follow the HSE advice, it is unlikely that you will contract the virus.

But if this does happen, you should continue to use your NIPPY.

However, you should be aware that the NIPPY blows air out from your lungs, and this air will contain coronavirus particles. This means that the room in which you use the NIPPY will be contaminated.

You should remain in this room when you are sick.

Other people in the house need to avoid being in this room if at all possible.

If they go in, they should use a mask and practice safe distancing as much as is practical.

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

All the people in your house are at risk of contracting and spreading the virus and they should also self-isolate. This means that they should not go outside for 14 days, even for shopping.

**Please let your IMNDA /Beaumont nurse know if you have tested positive and we will give you additional telephone advice.**

### **I am using Cough Assist. What happens if I get COVID-19?**

If you are using a cough assist machine you should follow the same advice as for NIPPY.

Use it only in one room. If possible, use the cough assist on your own or if you need help, limit this to one person who should wear a mask if possible. Other people should avoid going into this room for one hour after you have used the cough assist. The Physiotherapist is available for advice if required.

### **I cannot attend my clinic appointments for review, and my GP cannot visit me. What should I do?**

The IMNDA and the National MND Centre at Beaumont Hospital and Cork University Hospital have come together to **form a team of 7 nurses, 3 consultants and 4 doctors.**

This medical team will provide **remote clinics by telephone / video link for all MND patients.**

These clinics will take place on a Thursday (Beaumont) and Tuesday (Cork) and Wednesday (Galway). Some face to face clinics will also operate.

Multidisciplinary team members including Physiotherapy, Occupational Therapy, Speech and Language Therapy and Dietetics will provide advice, assessment and management by phone or video on request from the doctors and nurses.

The IMNDA and Beaumont Hospital Specialist nurses will continue to provide telephone advice during the week .

**An emergency out of hours service is available through the Beaumont Hospital Neurology On Call Service ( Through St.Brigid's Ward, Beaumont Hospital: Telephone: 018092425)**

**If you have an emergency, and cannot contact your GP/ Palliative Care Doctor, you can call this number, ask for the Neurology Registrar, and they will contact a senior member of the MND team out of hours for additional advice.**

If you need to be visited at home, the team can arrange this during working hours.

### **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 MND team will know about everybody's situation, and who is at the highest risk. The team will work with the HSE to make sure that you receive care, even if the normal caregivers are temporarily out of action.

### **With MND, will I be at risk if I'm given oxygen therapy for COVID-19?**

Prolonged use of oxygen therapy can be risky with MND. It can cause an upset in the balance between oxygen and carbon dioxide in your blood stream. However, there may be situations where oxygen can be used for short amounts of time to bring levels up.

It is ok to use oxygen with your Non-invasive ventilation.

### **I have read that people with COVID-19 might need to go on mechanical ventilation. But I have also read that mechanical ventilation is not a good idea for those with MND.**

Both of these are unfortunately true. The best way to avoid this problem is to avoid getting COVID-19.

But if you do become infected, the MND team will visit you at home and discuss with you and your family what the best options are for you.

### **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.
- You should tell them that you are using NIV and if possible the machine should not be in use in the room when the carer sees you.
- They may wear a mask when they visit you. Do not be alarmed about this.
- The NIV should be used on one room only and all surfaces should be wiped down regularly with bleach

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

- Schools have been closed 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

### **I am a carer of somebody with MND. What should I do?**

- Follow the HSE guidelines about social isolation
- Take regular exercise
- 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 your loved one is using NIV, you should be aware that this spreads droplets around the room. So if possible, the NIV should be used in only one room in the house, and surfaces should be cleaned down regularly.
- If you think your loved one has developed symptoms of COVID you should call your GP, and your MND nurse. The GP will decide if testing is required.

### **What else should I think about?**

If you haven't already done so, now is an important time to talk to your family about your wishes should you become ill and not be able to speak for yourself. If you have an advanced decision plan you should review this and update it. You should also discuss what might happen should your family members become ill.

We understand that this may be a frightening time for people with MND and their families. We are working hard to make sure you get the best care we can offer whilst protecting everyone from the virus as much as we can.

### **Whom can I contact for more advice or help?**

To make sure that people with MND continue to receive excellent care, the clinical and research doctors and nurses providing the national MND service in Beaumont Hospital and Cork University Hospital have joined forces with the IMNDA Nurses to provide ongoing phone and telemedicine care, along with home visits throughout the country.

If you have any concern during the day you can call your IMNDA or Beaumont MND nurse.

We can also help to solve emergencies out of hours.

### **Emergency phone number (Out of hours)**

**Call Beaumont Hospital (St.Brighids Ward) 018092425. You should ask to contact the Neurologist on Call .**

**The Registrar will contact members of the Medical MND team who will be available out of hours for additional advice.**

## **VACCINATIONS**

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

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 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.

### 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 with MND 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.