

FREQUENTLY ASKED QUESTIONS ABOUT CORONAVIRUS (COVID-19) AND MND March 30 2020

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

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

How do people get coronavirus?

You have to have been in close contact with somebody who has been affected with for more than 15 minutes.

What can I do to protect myself?

People with MND are classed as a “vulnerable group.

The HSE guidelines for how to protect from getting COVID-19 are here

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

- **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.

Should I continue to take Riluzole?

Yes. Taking Riluzole does not change your risk for COVID19

What should I do if my prescriptions run out and I cannot contact my GP?

You can call your IMNDA or Beaumont nurse, and they will arrange to send a prescription to you and your pharmacy. You can also contact the email advice MNDADVICE@gmail.com

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.

From discussion with doctors in Italy and Spain, there have been no or very few cases of coronavirus in MND patients in these regions.

This shows that social isolation works.

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.

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

Most people get better.

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 of (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 out patient appointment.

You can also call your IMNDA 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.

If you have any problems out of hours please call the emergency phone number 0874393213

I am using Non invasive ventilation. 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 6 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).

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 nurses will continue to provide telephone advice during the week and will also provide an **emergency out of hours help line. : 087 4393213**

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

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.

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 you 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 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 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 now for 2 weeks 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

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. There is also an emergency phone number that will be on all the time.

Emergency phone number: 087 4393213

Or if you have any other concerns relating to MND and COVID 19 you can also email MNDADVICE@gmail.com