

FREQUENTLY ASKED QUESTIONS ABOUT CORONAVIRUS AND MND

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 coronavirus 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?

The HSE guidelines for how to protect from getting coronavirus are here

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

- Stay at home
- Do not shake hands or hug people
- Do not touch your face with your hands
- Tell visitors not to visit if they have any symptoms of coronavirus.
- Ask visitors to wash their hands properly.
- Ask visitors to keep a space of at least 2 metres (6.5 feet) between you and them.
- Make a joint plan with family, friends and neighbours on what to do if you become ill.
- Do not have any more than 2 visitors at a time to your home.

What happens if somebody in my family gets coronavirus?

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 coronavirus?

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 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.

I am using Non invasive ventilation. What happens if I get coronavirus?

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

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.

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)

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.

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

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

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.

I have read that people with coronavirus 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 coronavirus.

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
- Tell visitors not to visit if they have any symptoms of coronavirus.
- Ask visitors to wash their hands properly.
- Ask visitors to keep a space of at least 2 metres (6.5 feet) between you and them.
- Make a joint plan with family, friends and neighbours on what to do if you become ill.
- Do not have any more than 2 visitors at a time to your home.
- 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 happens if I have carers? Do these increase my risks?

- Carers have been educated about spreading coronavirus, 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 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