

FREQUENTLY ASKED QUESTIONS ABOUT CORONAVIRUS (COVID-19) 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 ALS ?

Some of the symptoms of COVID-19 might seem similar to those of ALS – 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?

Each country will have guidelines to protect from getting COVID-19 . These involve the following:

- Follow local guidelines
- 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.

Should I continue to take Riluzole?

Yes. Taking Riluzole does not change your risk for COVID19

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

They should follow the advice of your local health service and isolate themselves.

In general, 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 your local health service advice about social isolation to protect you from getting coronavirus.

Across ENCALS sites, there have been no or very few cases of coronavirus ALS patients .

This shows that social isolation works.

If you do develop symptoms, you should follow the advice of your local health services.

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

I am using Non invasive ventilation. What happens if I get COVID-19?

If you follow the advice of your local health services, it is unlikely that you will contract the virus.

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

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

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

Prolonged use of oxygen therapy can be risky with ALS. 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 ALS.

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, your local ALS team can give you advice that is relevant to you and your local health services.

I am a carer of somebody with ALS What should I do?

- Follow your country's guidelines about social isolation
- Take regular exercise at 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
- Tell visitors not to visit if they have any symptoms of COVID-19.
- 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 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.

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

- Schools have been closed now in most European countries to stop children spreading the virus
- Follow your local healthcare service guidelines
- 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 ALS and their families. Everybody associated with ENCALS is working hard to make sure you get the best care we can offer whilst protecting everyone from the virus as much as we can.