

Coronavirus (COVID-19) and MND

The current outbreak of COVID-19 (coronavirus) is an illness caused by a new strain of the virus. We understand that you may be concerned about this virus and have many questions. We have tried to answer as many as we can for you in this letter.

We are writing to you because COVID-19 can affect your lungs and airways and complications can develop for some people with underlying conditions. You are considered at risk with COVID-19 if you have a chronic neurological disease, such as motor neurone disease (MND). You may have concerns if you are living with MND, or you help to support someone with MND.

We have tried to answer some common questions. However, as COVID-19 is a new virus, facts and guidance are still emerging and changing.

The MND Association have also produced advice that they will update. You can find these here: <https://www.mndassociation.org/mnd-and-coronavirus/>

You should also follow the instructions from the NHS website:
<https://www.nhs.uk/conditions/coronavirus-covid-19/>

As the situation changes you must still follow government guidelines to protect yourself, your family and the NHS staff who care for you.

1. How can I prepare for COVID-19 (coronavirus)?

Take the following steps or ask your carers to help:

- Contact your doctor and request any necessary medications (ask how to best order these from a reputable provider or pharmacy if they are unable to supply at the moment). If you can do this online then this will help support your GP to reduce their workload.
- Have enough household supplies and groceries to stay home for a period of time
- Download telecommunication applications that enable video messaging on your mobile phone or tablet, for remote consultation with your doctor and care team

What are the symptoms?

- COVID-19 usually includes a fever (high temperature), a dry cough and feeling short of breath. In some cases, this can lead to complications, including a type of pneumonia.

Is there any treatment?

- At present there are no medications that can treat the virus. The best way to manage if you have symptoms is to rest, take paracetamol to help with your symptoms. The current advice is to avoid taking ibuprofen for symptoms but if you need to take it for another condition then continue.

2. What should I do if I show symptoms of COVID-19 (coronavirus)?

- Do not visit a surgery or clinic, as this could spread the virus and may mean they have to close. Tell your carers and try to isolate yourself from others as best you can.
- If you get a fever or develop unexpected and continuous coughing, call 111 NHS or in an emergency 999. Ensure they know you have a condition that places you at risk. You can also contact your GP, they often have advice on their website about the best way to contact them.
- Tell your care agency and any carers that arrive at your house. Call in advance and if you can, put a sign on the door advising that you have symptoms.

<https://www.gov.uk/government/publications/covid-19-stay-at-home-guidance>

Do I need to self-isolate and if so, how will I get support?

As you are at higher risk with MND, you need to self-isolate at home. It is very important that you try to avoid the infection. This includes any medical visits unless your doctor assesses you and tells you that they are absolutely necessary. For the time being, limit personal contact to those who live in the same household or those who are **essential** to your care.

People who do need to be in close contact with you should also self-isolate as much as possible, and follow guidance to reduce risk of bringing infection into your home. However, they may need to help you with shopping and picking up medical supplies. <https://www.gov.uk/government/publications/covid-19-guidance-on-social-distancing-and-for-vulnerable-people/guidance-on-social-distancing-for-everyone-in-the-uk-and-protecting-older-people-and-vulnerable-adults>

If your main carer is unable to assist you for any reason, contact your local authority for help see numbers at the end of this document and: <https://www.gov.uk/find-local-council>

If you have a professional care worker who becomes unable to support you, contact the care agency first for guidance. If the agency cannot provide alternative support, contact your local authority for help.

3. I am taking Riluzole, what should I do?

Riluzole does not confer any additional risk related to the virus. You should make sure you plan ahead for repeat prescriptions unless your Riluzole is automatically delivered.

Do I still need my Riluzole safety blood tests?

Ideally you would still have these. However, there are risks in going to your GP surgery or to the hospital in terms of being exposed to COVID-19 (coronavirus). You should talk with your GP and/or consultant team whether it is safe to miss the blood tests (in most cases this is likely to be very low risk) or whether it is best to stop taking Riluzole temporarily.

4. What should I do if I am a carer for someone with MND or Kennedy's disease?

Please read this letter and continue to provide support as long as you are free of the virus symptoms and have not been in recent close contact with anyone who has the symptoms.

However, take extra care with hygiene – see the Government's guidelines on social distancing for carer advice. It is particularly important to consider hygiene before and

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after supporting someone with MND to eat and drink. Also when assisting them with moving and handling from one location to another.

Alternative care may need to be arranged if you become unable to offer support, especially if the person with MND is unable to manage daily routines without your help. You should contact your local authority for help (see details below) Your external carers must take extra care. Try to limit them to essential care only that can't be done by your family. Ensure they have good hand washing facilities and are wearing gloves and aprons. If you are unwell you must inform the agency urgently and not admit the carer to your house unless it is an emergency. You should also check to see if your carer is unwell when they arrive. If they are you should not admit them to your house and contact the agency urgently.

5. I use a breathing (NIV) or coughing machine, is there anything else I should do?

Breathing and coughing machines can be very helpful in managing any symptoms you may have. If you have symptoms of a cough or shortness of breath you can use them as much as you feel necessary. If your symptoms worsen you can use your NIV all the time.

**You can contact your respiratory service hotline for support with your NIV.
Lane Fox Unit: tel 020 7188 2823 or 020 7188 2821.**

**The LFU technicians' contact number for NIV machine and tubing issues is:
020 7188 3434 - Option 4.**

They may be able to send out masks and other equipment to your home or give you routine advice about using the equipment.

****IMPORTANT****

If you have the COVID virus, NIV and cough machines can spread it.

To **prevent** this you should do the following **if you have Covid symptoms**:

- Try if possible not to use these machines when there is anyone in the same room or at least with only your one main carer. The carer should be wearing full PPE (personal protective equipment). If possible, do not use the machines when there are any visitors to your house. Try to limit the number of external carers to the absolute minimum and if you have symptoms of COVID virus you must tell them before they enter the house.
- If you need to come to hospital, you should bring your equipment in the car or ambulance. You must tell the ambulance and ward that you need NIV and/or cough assist and they will assess what to do next.
- You must tell 111, 999 and or your GP and ambulance drivers that you are using NIV so they can make arrangements.
- If possible use a mask that covers both your mouth and nose.
- Queries about continued use of NIV and cough assist can be discussed on an individual basis with the local care team and Lane Fox Unit staff.

Do I need to wear a protective facemask?

Wearing a protective facemask or filter may not be helpful and could make breathing more difficult if you already get breathless. However, if you use a breathing mask for assisted ventilation, then continue to use this as normal.

With MND, will I be at risk if I'm given oxygen therapy for COVID-19 (coronavirus)?

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.

Using oxygen should be done with the guidance of your care team, who understand your needs. Try to ensure you have an MND alert band and card on you at all times. If you do need emergency help, this will let medical staff know that you have MND and that oxygen may need to be used with caution. You can obtain one by calling MND Connect.

6. 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 care plan (ACP or RESPECT form), you should review this and update it. You should also discuss what might happen should your family members become ill.

We understand that this will 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.

Who can I contact for help?

You should still follow the NHS guidelines to call 111 if you are so unwell you are unable to carry out your daily activities or 999 in an emergency

- If you have one, contact your MND specialist practitioner (insert name) on: insert number
- You can contact the Sussex MND Network on 01273 876541
- Your GP can contact the BSUH neurology on call team 24 hours a day.
- Your hospice team can be contacted on:
Martlets hospice: 01273 273400
St Peter and St James hospice: 01444 471598
St Wilfrid's hospice (Eastbourne) 01323 434222
St Wilfrid's hospice Chichester: 01243 775302
Hospice in the Weald: 01892 820515
St Michaels's hospice: 01424 445177
St Catherine's hospice: 01293 447329.
- You can call **MND Connect on 0808 802 6262** who can provide information but not any medical advice.

- **Local councils adult social care:**

West Sussex County Council: 01243 642121

Brighton and Hove Council: 01273 29 55 55

East Sussex County Council: 0345 60 80 191

Professor Nigel Leigh (Director) and Rachel Thomson (Coordinator)

Sussex MND Care and Research Network

Contact Rachel Thomson on Rachel.thomson1@nhs.net or 01273 876541 for **NON URGENT** advice. We cannot guarantee that Rachel will be available all the time but messages will be responded to within 2 working days.