

Living with MND during the COVID-19 pandemic

What you should do

- Stay home except to get medical care that cannot be provided via telehealth
- Wash your hands regularly with soap and warm water for 20 to 30 seconds
- Clean all surfaces that you and others in your household touch regularly throughout the day
- Keep 30 days of medical supplies and medication on hand if possible
- If you have appointments to see your GP, neurologist or MND clinic ring ahead to arrange a telehealth appointment instead of a face to face consultation if possible
- Talk with your MND Association, NDIS or home care package providers to communicate your needs and expectations about the precautions needed to keep you and your carer safe when providing services to support you at home.

About COVID-19 and living with MND

To help keep the MND community informed a [COVID-19 page](#) has been developed on the MND Australia website with links to trusted and up to date information. The International Alliance of ALS/MND Associations has collated COVID-19 information from associations internationally and has started a [webinar series](#) to answer questions from the global ALS/MND community.

People living with MND often have a harder time with swallowing, breathing and coughing due to muscle weakness and are therefore at risk of developing serious complications if they become infected with the COVID-19 virus, regardless of their age. Every precaution should therefore be taken to prevent you and the people in your household from becoming infected with COVID-19.

If you are sick or think you have COVID-19

For people living with MND it is important that if you, or anyone in your household, develops a fever or flu like symptoms such as coughing, sore throat, fever or increased fatigue you should isolate yourselves and seek medical advice as soon as possible. If you are concerned that you may have symptoms or may have been exposed to COVID-19 you can call the National Coronavirus Health Information Line on 1800 020 080 or use the [healthdirect symptom checker tool](#). You should let your home care team and neurologist or MND Clinic coordinator know of your concerns as soon as possible.

People living with MND may already have some difficulty with breathing so if you experience any increased difficulties or sudden onset of breathing difficulties call 000 for urgent help.

What you should know about breathing and MND

- Over time MND causes the muscles that support your breathing to weaken. The respiratory muscles include the diaphragm and intercostal muscles. Problems with the respiratory muscles can occur at any stage of disease progression, and lead to symptoms such as fatigue, difficulty sleeping and shortness of breath.
- Positioning, adjusting air flow in the room, physiotherapy, breathing exercises, assisted coughing techniques, staying away from people with colds, influenza or respiratory tract infections and saving your energy are just some of the simple techniques you can use to manage mild respiratory symptoms.
- Getting advice about respiratory management soon after your diagnosis with MND can help you live better for longer. Let your doctor or clinic know if you notice changes to your breathing.
- Other strategies for managing breathing with MND include medically supervised use of medications such as opioids or benzodiazepines to minimise the sensation of breathlessness and reduce stress and anxiety, or supplementing breathing with non-invasive ventilation (for more information see the MND Australia [Evidence Based fact sheets](#) on breathing)

If you use a ventilator, non-invasive ventilation or cough assist device

- Speak to your health care provider or respiratory doctor or nurse about the precautions you, your carer and home care team should take in your home
- Clean your equipment and replace filters regularly as per your device manual
- Ensure you have an adequate supply of filters and tubing
- In case you develop symptoms of COVID -19 and require admission to hospital, ask your health care provider or respiratory doctor or nurse to give you a one page list outlining your respiratory management and machine settings to take with you
 - Include in the list information about use of oxygen as opposed to natural air flow for people with MND. Oxygen should be used with caution and will require appropriate monitoring.
 - You might also want to ensure that you have a copy of an up to date advance care plan to take with you to ensure your wishes are respected.

What should you do if you do not currently use any of these devices but think your respiratory muscles are weakening

In response to COVID-19, the Federal Government has introduced a much-expanded '[Medicare at Home](#)' measure which safeguards and ensures care for all those with chronic conditions such as MND. It means people living with MND can safely stay at home, and still have access to their allied health care team, GP, nurses and specialist doctors, such as neurologists and respiratory specialists via telehealth services.

If you do not have any symptoms of COVID-19 but think you may be developing symptoms of respiratory muscle weakness due to your MND, then you should contact your neurologist. Your neurologist may refer you to a respiratory specialist for an assessment of your respiratory function. There are a number of strategies that can help, as outlined in this fact sheet. Non-invasive ventilation may be prescribed to manage respiratory symptoms and improve your quality of life. Your neurologist may also advise you to consider having a gastrostomy tube inserted (PEG) to support eating and drinking should you also develop difficulties with swallowing (for more information see the MND Australia [Evidence Based fact sheets](#) on considering gastrostomy). It is safer to have this procedure before respiratory muscle weakness progresses too much.

During this COVID-19 crisis there is an increased and high demand from hospitals for machines to assist with breathing which may impact access to supply for the MND community. It is therefore important to stay in contact with your neurologist and/or respiratory doctor to ensure that they are able to monitor your respiratory function closely during this outbreak in case access to supply takes time.

If you experience any problems in accessing non –invasive ventilation, cough assist devices or associated equipment such as masks, talk to your [state MND Association advisor](#) who may be able to advocate on your behalf. As the national voice for the MND community, MND Australia is working with MND Clinics, the [national MND Association network](#) and members of the [International Alliance of ALS/MND Associations](#) to monitor the impact of the COVID-19 outbreak on access to services and support for people living with MND. We will work to bring any issues or impacts on the MND community that arise due to the current crisis to the attention of decision makers.

More information

Important Note

During the COVID-19 crisis having an advance care plan in place is more important than ever.

See the MND Australia Fact Sheet [Planning Ahead](#) or visit www.advancecareplanning.org.au

For more information about respiratory management contact your GP, neurologist, respiratory physician, palliative care team, MND clinic or your MND Association on 1800 777 175. MND Australia encourages people living with MND to talk to their doctor about COVID-19 to understand the implications for their unique circumstances.

To stay up to date on the COVID-19 outbreak and current advice visit the Australian Government Department of Health website [current status page](#), [healthdirect](#), the [World Health Organisation \(WHO\)](#) and the MND Australia [COVID-19 webpage](#). You can also download the [Australian Government Coronavirus \(COVID-19\) app](#).

MND Australia fact sheets

MND evidence-based interventions - an overview (EB1)
Multidisciplinary care (EB2)
Multidisciplinary care team (EB3)
Riluzole (EB4)
Breathing and motor neurone disease: an introduction (EB5)
Breathing and motor neurone disease: what you can do (EB6)
Breathing and motor neurone disease: medications and non-invasive ventilation (EB7)
Considering gastrostomy - PEG and RIG (EB8)
Planning Ahead

To find out about motor neurone disease and other fact sheets in this series contact the MND Association in your state or territory ph. 1800 777 175 or visit www.mndaustralia.org.au

Acknowledgments:

MND Australia evidence based fact sheets:

Breathing and motor neurone disease: [an introduction \(EB5\)](#)

Breathing and motor neurone disease: [what you can do \(EB6\)](#)

Breathing and motor neurone disease: [medications and non-invasive ventilation \(EB7\)](#)

Considering gastrostomy - [PEG and RIG \(EB8\)](#)

[Planning Ahead](#)

The Australian Government Department of Health Coronavirus (COVID-19) [health alert](#)

The International Alliance of ALS/MND Associations Coronavirus (COVID-19) [webinar series](#)

Healthdirect – [COVID-19 information](#)

International Alliance of ALS/MND Associations COVID-19 and Care resource page - [ALS Canada COVID-19 Guidance for the ALS Community](#)