



Dear patients,

We are sure that you are aware of the current global pandemic caused by a strain of Coronavirus- Covid-19.

Patients with neuromuscular disorders like ALS and muscular dystrophies with weakened respiratory systems are more susceptible to develop severe cases of COVID-19. Also, more susceptible are patients who are immunocompromised and/or receiving immunosuppressant treatments for diseases like myasthenia gravis, CIDP, myositis and other autoimmune neuromuscular disorders.

AANEM recommends following CDC guidelines closely and to continue your current treatments. Please discuss risks with your physicians before stopping any medications, including those that suppress the immune system. It is also important that you seek prompt medical attention by contacting your health care provider first if you or anyone in your household is identified with symptoms consistent with COVID-19 or for documented exposure to an individual who has tested positive.

If you are on noninvasive ventilations like Trilogy or PAP therapies like BiPAP/CPAP, make sure you are aware of potential viral aerosolization/spread with such therapy if you were to harbor this virus. Corona virus can be found in saliva, nasal and pharyngeal secretions in both symptomatic and asymptomatic individuals. We want to update you and your caregivers about the risks and ways to mitigate such risks. The masks and mouthpiece should be cleaned, disinfected, rinsed with sterile water and air-dried between uses.

We recommend following manufacturer recommendations based on your device. Upon a patient's recovery from COVID-19, it may be advisable to replace filters, given the lack of data regarding the possibility of re-infection.

<https://www.resmed.com/en-us/sleep-apnea/cpap-parts-support/cleaning-cpap-equipment/>

<https://www.usa.philips.com/c-e/hs/better-sleep-breathing-blog/better-sleep/keeping-it-clean-cpap.html>

COVID-19 symptoms are typically fever, cough and breathing difficulty similar to any respiratory illness/flu. COVID-19 however has a wide range of severity from a mild cold-like illness to severe breathing difficulty that can lead to death.

Coronavirus primarily spreads from person to person via droplets breathed out, coughed out or sneezed out and by contaminated surfaces. Late in the illness there is the potential for exposure from stool. The best way to avoid contracting COVID-19 is to avoid close contact and keep a distance of at least 6 feet from other people. Stay home. Avoid touching your eyes, nose, and mouth. Cover your cough or sneeze with a tissue, then throw the tissue in a closed trash bin. Clean and disinfect frequently touched objects and

surfaces using a regular household cleaning spray or wipe. Wash your hands often with soap and water for at least 20 seconds, especially after going to the bathroom; before eating; and after blowing your nose, coughing, or sneezing. If soap and water are not readily available, use an alcohol-based hand sanitizer with at least 60% alcohol.

It is important that caregivers and household members take all necessary precautions to avoid the risk of contracting COVID-19 and spreading the illness to someone with a neuromuscular disease. Please also identify a backup caregiver for you who will be able to provide care in case your caregiver becomes sick. We recommend that you seek prompt medical attention by contacting your health care provider first if you or anyone in your household is identified with symptoms consistent with COVID-19 or for documented exposure to an individual who has tested positive. **If you have a medical emergency and need to call 911, notify the dispatch personnel that you or a member of your household has, or is being evaluated for Covid-19.**

AANEM is wants to make sure you stay healthy. Please review information on how to take precautions and seek care if you need it from your treating physician.

Please also utilize following web-based resources for more information about Coronavirus and Covid-19 to learn more and address your concerns.

<https://www.cdc.gov/coronavirus/2019-ncov/index.html>

<https://www.who.int/health-topics/coronavirus>

Stay safe. We are thinking of you during this challenging time.

AANEM