



COVID-19 and Neuromuscular Patients

April 3, 2020

There is an abundance of information available on COVID-19, but little guidance specific to Canadians with neuromuscular disease (NMD), their families, and their caregivers. We at the Neuromuscular Disease Network for Canada (NMD4C) and Muscular Dystrophy Canada (MDC) hope to support the community by compiling this information, recommendations, and links to additional sources. Information is provided to the best of our current knowledge, but recommendations may change as the situation evolves. For tailored advice and treatment, you need to reach out to your health care provider.

If you have any additional questions about COVID-19, please send them to research@muscle.ca and an NMD expert will respond with an answer shortly. You can find the current answers [HERE](#).

About COVID-19

COVID-19 is an infectious disease in humans caused by a novel coronavirus, similar to other strains of coronavirus that caused the 2012 outbreak of Middle East Respiratory Syndrome (MERS) and the 2002 outbreak of Severe Acute Respiratory Syndrome (SARS). COVID-19 is highly infectious for children and adults as nobody has immunity to the new virus, leading to the rapid spread between people across the globe.

The most common symptoms of COVID-19 are fever, fatigue, and dry cough. Infected people may also experience aches and pains, nasal congestion, runny nose, sore throat, loss of smell and/or taste, and diarrhea. Symptoms are usually mild and begin gradually, and about 80% of infected people recover without treatment. However, one in six people with COVID-19 require hospitalization or intensive care due to developing more serious symptoms such as difficulty breathing, pneumonia, or organ failure. Sadly, about 1% of

people who contract COVID-19 do not survive, though this risk varies depending on additional factors such as age and health care.

Find additional general information about COVID-19 from the World Health Organization [HERE](#).

Prevention

There is not yet a vaccine or any specific treatment for COVID-19. At this time, the best way to prevent infection is to avoid exposure. COVID-19 spreads when an infected person coughs, sneezes, or talks, expelling tiny droplets that someone else inhales or that land on a surface that someone else touches.

To avoid person-to-person infection, it is important to self-isolate (i.e., stay in your home) as much as possible. When you must go out, maintain social distancing of at least 2 meters (approximately 2 arm lengths). This distance makes it so that any expelled droplets cannot reach another person. Many people are contagious for weeks before feeling symptoms, so it is crucial to self-isolate and practice social distancing even if you feel well.

To avoid infection from exposed surfaces, frequently and thoroughly wash your hands and disinfect surfaces. Wash your hands for at least 20 seconds with soap and water. If soap and water is not available, use alcohol-based hand sanitizer with at least 60% alcohol. Do not touch your nose, eyes, or mouth, as this can transmit infection from surfaces you have touched into your body. Wipe surfaces with soap and water first, then with household disinfecting spray or wipes. If these are not available, you can dilute 2 teaspoons of bleach into 4 cups of water to use as surface disinfectant. Pay extra attention to high-touch surfaces such as doorknobs, counters, remote controls, etc.

Cough or sneeze into the bend of your elbow or into a tissue, and then throw out the tissue and wash or sanitize your hands. Facemasks are strongly recommended to be worn by people who are sick, health care providers, and caregivers. Facemasks primarily prevent passing the virus on to vulnerable people.

Watch [this video](#) by the World Health Organization about preventing the spread of COVID-19.

COVID-19 in the neuromuscular disease community

It is now recognized that the risk of complications from COVID-19 is high or moderately high for most neuromuscular patients. Generally, people infected with COVID-19 are more at risk of developing complications if they are older, have weakened immune systems, or have underlying chronic medical problems (e.g., heart disease). Neuromuscular patients may also be especially at risk if they:

- Take oral steroids or other immunosuppressants or are **otherwise immunocompromised**.
- Have respiratory complications (e.g., ventilated, Forced Vital Capacity less than 60%, weak cough and weak airway clearance, kyphoscoliosis, congenital myasthenic syndrome, myasthenia gravis)
- Have cardiac complications
- Have difficulty swallowing (e.g., myotonic dystrophy, oculopharyngeal muscular dystrophy)
- Are at risk of decompensation, deterioration, or rhabdomyolysis during fever, fasting, or infection (e.g., mitochondrial disease)

For neuromuscular patients, the following is recommended:

- The regular precautions that apply to everyone (e.g., social distancing, handwashing, disinfecting surfaces) are especially important for people with NMD and the people with whom they live.
- Make sure you are comfortable with the emergency procedures specific to your condition and equipment in case you get sick (e.g., when and how to use your breathing devices, how to deal with adrenal suppression for people on long-term steroids).
- Make sure you have a good supply of all medication and equipment, ideally 3 months worth. This is especially important for drugs obtained through Health Canada's Special Access program such as deflazacort. Canadian pharmacies may offer online or telephone ordering and delivery services.
- Have an alert card on hand to communicate your medical needs and symptoms in case of emergency.
- Get in touch with your neuromuscular health care provider if you have a specific question or concern (e.g., about your medication).

Read additional posts about COVID-19 and NMD by [Muscular Dystrophy Canada](#), [World Muscle Society](#), [Muscular Dystrophy UK](#), [EURO-NMD](#), and [European Alliance for Neuromuscular Disorders Associations](#).

Starting on page 5 in [this document](#) is information about COVID-19 for some specific conditions (this does NOT replace discussion with your health care provider).

Read about respiratory support during COVID-19 [HERE](#), and for myotonic dystrophy patients [HERE](#).

Read about COVID-19 and Amyotrophic Lateral Sclerosis (ALS) [HERE](#).

Watch this [1-hour webinar](#) about COVID-19 and Becker Muscular Dystrophy and Duchenne Muscular Dystrophy.

Read about COVID-19 and Duchenne Muscular Dystrophy [HERE](#).

Read about COVID-19 and Myasthenia Gravis and Lambert-Eaton Myasthenic Syndrome [HERE](#).

Read about COVID-19 and Spinal Muscular Atrophy [HERE](#).

Download [this sign](#) for your door notifying visitors or delivery persons of the need for additional precautions at your home.

Medication



Do not take any unproven COVID-19 medications circulating on social media (e.g. chloroquine). These can be particularly dangerous for people with some NMDs. Always talk to your health care provider before making any changes to your medication.



If you are currently taking any medication for your NMD (e.g., steroids), you should continue to take them as normal unless otherwise instructed by your health care provider. Many medications for NMD compromise the immune system which does increase the risk related to viral infections. However, it can be more dangerous to suddenly stop taking prescriptions without medical counsel. The safest course of action is to contact your health care provider to discuss your specific case.

In this time of uncertainty, dangerous information is circulating on social media suggesting that people should try unproven medications to prevent or treat COVID-19. One of these is an anti-malaria medication called chloroquine. Chloroquine has not been proven to help

patients with COVID-19. It is important to note that chloroquine may worsen symptoms such as weakness and breathing difficulties in myasthenia gravis patients and people with other neuromuscular transmission disorders such as congenital myasthenic syndromes and Lambert-Eaton syndrome. Any other medication suggested on social media may have dangerous effects that could be even worse for people with NMDs. Please talk to your health care provider before making any changes to your medication. This is good advice for everyone but even more important for people with a neuromuscular condition.

There are also reports circulating online that you should not take ibuprofen or Advil if you have COVID-19, but there is no scientific evidence to back this [according to Health Canada](#). However, you should still follow any guidelines specific to your NMD (e.g., people with Duchenne often should not take ibuprofen, regardless of the presence of a viral infection).

Starting on page 17 in [this document](#) is some general information about certain medications for NMD (this does NOT replace discussion with your health care provider).

Read [this article](#) about medications for hypertension, heart disease, and kidney disease during COVID-19.

Read [this article](#) about COVID-19 medications for myasthenia gravis patients.

COVID-19 and neuromuscular disease caregivers

People who provide care for neuromuscular patients, whether professionally or not, need to be extra diligent about following the regular precautions that apply to everyone regarding COVID-19 prevention. This is both because neuromuscular patients may be at higher risk if they were to contract COVID-19, and because professional caregivers may be visiting multiple homes each day. Caregivers should also wear a facemask when in contact with neuromuscular patients, whether or not they feel sick.

Neuromuscular patients and their families should identify a backup caregiver in case their primary caregiver becomes sick. In advance, make sure the backup caregiver has all the information they need to take over care with short notice. Ideally, necessary information should be written down and easily accessible for reference. Necessary information includes:

- Contact information for your doctors, clinic, pharmacy, etc.
- Names and doses of all medications

Caregivers should stop working/caregiving immediately if they feel sick.

Read posts about NMD caregiving during COVID-19 from [Muscular Dystrophy Canada](#) and the [Ontario Caregiver Organization](#).

What to do if you feel sick

Neuromuscular patients should promptly seek medical attention if they or someone to whom they have been exposed is identified with symptoms of COVID-19. This is especially important if you normally have lower breathing capacity as COVID-19 may make your breathing even more difficult. Call your health care provider to let them know that you may have been exposed and they will provide guidance about the next steps you should take (e.g., testing, monitoring, seeking in-person medical attention).

If you experience any of the following emergency warning signs, call 911 or go to an emergency room or urgent care facility:

- Difficulty breathing or shortness of breath
- Persistent pain or pressure in your chest
- New confusion or inability to arouse
- Blue lips or face
- Anything else you find severe or concerning

If you leave your house to seek medical attention, ensure you do the following:

- Call ahead to give the health care facility advance warning about your symptoms/exposure. If you are going to the hospital, also notify your regular health care provider of the situation.
- Wear a face mask to help prevent spreading your infection to others.
- Bring your breathing equipment (labelled with your name and phone number) and know/write down your device settings. You may wish to ask when you call ahead about whether your specific equipment will be welcomed. For example, some devices such as cough assist machines can increase the spread of an infection from you to your environment.
- If you have myotonic dystrophy, bring [this document](#) to provide the health care staff with specific information about your respiratory needs. This information may also be relevant for patients of other NMDs requiring respiratory support.

If you are sick and advised by a medical professional to try recovering at home, stay in one specific room of the house. Other people should only enter the room when necessary and take all the proper precautions when doing so. Pets should not enter the room as we do not yet know if pets can contract COVID-19, and they may increase the spread of the infection within the house.

Impact on ongoing clinical trials

Hospitals across the country are currently prioritizing their resources to fight COVID-19 and take care of other acute, severe, and life-threatening conditions such as heart attacks and strokes. They also need to limit access to the hospital for visitors, out-patients with less severe conditions, study personnel, and trial participants. Moreover, travel to the study site may be restricted or become unsafe. If you or your child are a participant in an active clinical trial, your study doctor and/or study coordinator will likely contact you if any of the following events occur:

- If a visit to the study site is planned, whether the visit is cancelled, postponed, or changed in any other way such as being replaced by a phone call or telemedicine visit
- If any changes to your study medication are required
- If the study has been terminated

You must contact your study doctor and/or study coordinator if any of the following events occur:

- If you have questions about the study
- If you feel unwell
- If you have been diagnosed with or are suspected to have contracted COVID-19
- If your caregivers or members of your household have been diagnosed with or are suspected to have contracted COVID-19

Health Canada provided guidance for Canadian clinical trials during the COVID-19 pandemic [HERE](#).

The FDA provided guidance for American clinical trials during the COVID-19 pandemic [HERE](#).

Mental health

During this COVID-19 pandemic, many people are left feeling quite stressed as they worry about health, finances, school and work deadlines, supplies, and an uncertain future. Please know it is completely normal to feel stress and negative emotions in situations like this. Some strategies for maintaining mental health at this time include:

- Stay socially connected with phone calls and video chats.
- Practice mindfulness with your favourite of the many available mindfulness mobile apps.
- Set specific time limits for scrolling social media and monitoring COVID-19 news. Stop when your time limit is over and focus on other things.
- Practice deep breathing and/or go for walks outside (while maintaining social distancing).
- Do not try to avoid or push away negative thoughts or feelings. Acknowledge them, express them, then practice gratitude and positive self-talk.

Read posts by [Muscular Dystrophy Canada](#), the [Centres for Disease Control](#), and the [Institut National d'Excellence en Santé et en Services Sociaux](#) about mental health during the COVID-19 pandemic.

Read about maintaining social connections while physically distancing [HERE](#).

Keep updated

[World Health Organization updates](#)

[Government of Canada updates](#)

[Government of Alberta updates](#)

[Government of British Columbia updates](#)

[Government of Manitoba updates](#)

[Government of New Brunswick updates](#)

[Government of Newfoundland and Labrador updates](#)

[Government of Northwest Territories updates](#)

<https://neuromuscularnetwork.ca/news/covid-19-and-neuromuscular-patients-la-covid-19-et-les-patients-neuromusculaires/>

[Government of Nova Scotia updates](#)

[Government of Nunavut updates](#)

[Government of Ontario updates](#)

[Government of Prince Edward Island updates](#)

[Government of Québec updates](#)

[Government of Saskatchewan updates](#)

[Government of Yukon updates](#)

Sources

[Muscular Dystrophy Canada](#)

[Muscular Dystrophy UK](#)

[Muscular Dystrophy Association](#)

[World Muscle Society](#)

[Parent Project Muscular Dystrophy](#)

Ottawa Hospital Neuromuscular Rehabilitation Clinic

[Institut National d'Excellence en Santé et en Service Sociaux](#)

[World Health Organization](#)

[Centers for Disease Control and Prevention](#)