

FREQUENTLY ASKED QUESTIONS COVID-19 & NEUROMUSCULAR DISORDERS

Muscular Dystrophy Canada has received numerous questions about COVID-19 and how it may uniquely affect people with neuromuscular disorders (NMD). The COVID-19 virus is still very new and there are a lot of things we don't know specific to Canadians with neuromuscular disorders, their families, and their caregivers. Researchers are still studying this new coronavirus and how it affects people who are vulnerable. We asked neuromuscular specialists, respirologists and researchers from across Canada and the Neuromuscular Network For Canada (NMD4C) to provide recommendations and information about COVID-19 for people impacted by neuromuscular disorders based on available evidence and to the best of their current knowledge. Please note that these recommendations should supplement, but not replace the recommendations made by your doctor or your local public health authority. Please speak to your healthcare provider if you have any further questions.

QUESTIONS ABOUT RISK

Q: Am I at higher risk to contract COVID-19 and develop complications from COVID-19 if I have ... (*Spinal Muscular Atrophy, Duchenne Muscular Dystrophy, FSHD, Myasthenia Gravis, Becker Muscular Dystrophy, Pompe, McArdle Disease etc.*)

The Neuromuscular Network For Canada (NMD4C) indicates that there is not yet any specific scientific evidence regarding the risk factors for neuromuscular patients if they were to contract COVID-19. However, as COVID-19 can cause difficulty breathing, people with neuromuscular disorders are likely a higher risk group because they may already have weakened respiratory or cardiac muscles.

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). People with neuromuscular disorders may also be especially at risk if they:

- Take oral steroids or other immunosuppressants
- Have respiratory complications (e.g., ventilated, Forced Vital Capacity less than 60%, congenital myasthenic syndrome, myasthenia gravis)
- Have cardiac complications
- Have difficulty swallowing (e.g., myotonic dystrophy, oculopharyngeal muscular dystrophy)
- Are at risk of decompensation during infection (e.g., mitochondrial disease)

The Association of British Neurologists (2020) specifically outline the following neuromuscular disorders and their associated risk for COVID-19:

Neuromuscular Disorder	Risk for COVID-19 (High, Medium, Low)	Comments
Myositis, polymyositis	Medium -High	If the disease is active – there is increased risk due to respiratory muscle weakness as well as co-existing interstitial lung disease which is common in these patients and other overlap connective tissue disorders.
X-linked muscular dystrophies (Duchenne, Becker)	High	High risk if FVC<60%, non-invasive ventilation, weak cough or cardiomyopathy.
Limb-Girdle muscular dystrophies	Medium - High	High risk: FVC<60%, NIV, weak cough, cardiomyopathy
Myotonic dystrophy	Medium – High	High risk if FVC<60%, Poor cough, risk of chest infection, risk of choking with coughing.
Congenital muscular dystrophy	High	High risk for patients with FVC<60%, those NIV and with weak cough. Patients with cardiomyopathy.
Spinal muscular atrophy	Medium – High	Type 2 SMA high risk Type 3 high risk if FVC<60% or using BiPAP (usually non-ambulant)
Congenital myopathy	Medium – High	High risk if patients with FVC<60%, those NIV and with weak cough.
Mitochondrial disease	Medium – High	Risk of decompensation during infection, risk of cardiomyopathy Patients with diabetes at high risk Patients immunosuppressed for organ transplantation at high risk
Glycogen storage disease (i.e., Pompe)	Low – Medium - High	Patients with Pompe disease with FVC<60% or on BiPAP at risk of respiratory decompensation Patients with secondary diabetes and ischaemic heart disease at high risk

Guillain-Barre Syndrome	Medium	Likely only to be at risk if acutely ventilated and whilst there is neuromuscular respiratory weakness. No additional risk of causation or recurrence known. No usual immunosuppressant.
Chronic Inflammatory Demyelinating Polyneuropathy	Low – Medium	Risk inferred by immunosuppression agents
Inherited neuropathies (i.e., Charcot-Marie-Tooth Syndrome)	None	No risk to uncomplicated Charcot-Marie-Tooth. Patients with kyphoscoliosis and/or neuromuscular chest/diaphragm weakness may be at high risk.
Myasthenia Gravis	Medium – High	Well controlled MG (M); Myasthenia gravis on immunosuppression and/or with respiratory involvement is at a greater risk from COVID-19 infection (H)
Lambert Eaton myasthenic syndrome	Medium – High	
Congenital myasthenic syndrome with previous respiratory involvement or needing nocturnal ventilation	High	
Ocular myasthenia	Low	Or well controlled adult congenital myasthenia without respiratory involvement in last 10 years

Q: I am very stressed about being high-risk for COVID-19. Is this normal?

Many people are 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 physical distancing).
- Do not try to avoid or push away negative thoughts or feelings. Acknowledge them, express them, then practice gratitude and positive self-talk.

QUESTIONS ABOUT CAREGIVERS

Q: We have personal care aides/personal support workers/home care aides that come into our home. What precautions should we take?

People who provide care for neuromuscular patients, whether professionally or not, need to be extra careful 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.

Have a sign posted at the entrance of your home for your caregivers and attendants to self-screen and review the precautionary measures they can take while in your home. Contact research@muscle.ca if you would like a copy of a sign.

Have your caregivers and attendants greet you without touching (e.g., a wave hello).

Have your caregivers and attendants wash their hands for at least 20 seconds (the time it takes to sing "Happy Birthday" twice) with soap throughout the day.

Have your caregivers and attendants use hand sanitizer (at least 60% alcohol-based) when they arrive at your home and each time prior to touching or feeding you.

Have your caregivers and attendants clean, sanitize and disinfect the surfaces that are touched in your house and use disinfecting wipes on items that are frequently touched (e.g., cell phones, doorknobs, your wheelchair controls, lifting device controls, and remote controls). Make this convenient by having wipes near the items that should be regularly cleaned.

If your caregiver or attendant becomes sick, ask them to seek medical care in advance. 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.

If caregivers need information about supports and services in their community, they can call the Caregiver Helpline. The 24/7 helpline is 1.833.416.2273 or they can access the live chat at ontariocaregiver.ca between 9am and 7pm Monday to 4

Friday. More information about COVID-19 and [what it means for caregivers is available on the Canadian Support Workers Association website.](#)

Q: We were not able to find any masks, hand sanitizers and gloves. What can I do to help protect myself when my home care aides and personal support workers come into my home?

Using soap and water has been demonstrated to be the most useful way to kill the virus on hands and surfaces. Frequent and thorough handwashing is very important. If a mask is not available, limit talking during close encounters required for personal care as this can limit the projection of particles.

QUESTIONS ABOUT IMMUNITY/PROTECTION AGAINST COVID-19

Q: Could probiotics or supplements with Vitamin D, Vitamin C, and oregano oil help boost immune system and “fight off” the virus?

No, unfortunately. There is no scientific evidence to support claims that any specific foods or vitamins can help reduce the risk or severity of any virus. The World Health Organization advises that avoiding smoking, eating healthy foods, exercising and maintaining low stress levels are important lifestyle practices in general and helpful for the immune system during a pandemic crisis.

Q: Will humidity help those with neuromuscular disorders?

No, we don't believe humidity will help. There is not enough high-quality evidence to show humidity will help the immune system to fight respiratory viral infections. In fact, Alberta Health Services Provincial Critical Care Communicable Disease Working Group put together recommendations for Care of the Critically Ill Adults and COVID-19 – they note “avoid use of heated humidity systems other than when they are fixed integral systems of a particular ventilator.” If ill with a virus, use of noninvasive ventilation is actually a risk for transmission because it is an aerosol generating treatment.

Q: I am ventilated at home. Should I self-isolate for longer than 14 days?

It would be advisable to carry out physical distancing as long as the pandemic situation persists. Complete isolation may not be possible for ventilated people who are depending on care.

Q: I have Myasthenia Gravis. If someone in my home is vaping – does that increase my risk of contracting COVID-19?

There is very little research that has directly examined whether smoking or vaping increases a person's risk of severe COVID-19. However, there is substantial scientific evidence that smoking tobacco and e-cigarettes (vaping) and second-hand smoke increases risk for respiratory viral infections because it suppresses immune function in the lungs and triggers inflammation. We encourage individuals, particularly those who are considered high risk (e.g., those with Myasthenia Gravis) and susceptible to virus exposure, to do their best to avoid smoke-filled indoor environments. You should follow prevention measures such as physical distancing as much as possible.

QUESTIONS ABOUT DRUGS/MEDICATIONS

Q: Should we be concerned about drug shortages for medications (e.g., Deflazacort which is accessed through the Special Access Program)

We know access to medications is important for many people living with neuromuscular disorders. If the pandemic lasts, there might be shortages for certain medications. But currently, we are not aware of any drug shortages. If you are on regular medication it is worthwhile discussing with your pharmacy to make sure you can get access to what you need and have at least 2-4 weeks supply – and if possible 3 months supply. It is also helpful to ask if they can deliver the medication to your home to minimize contact.

Q: Do you know if clinic visits for Zometa (bisphosphonates) infusions will be postponed?

Biphosphonate infusions are usually given annually, so postponing them for a few weeks might be in the best interest of patient and hospital under the current circumstances. You should call your healthcare providers or clinical assistant to find out when your appointment can be rescheduled for.

Q: Is chloroquine a treatment for COVID-19? What does that mean for someone with Lambert-Eaton syndrome?

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.

Q: Should I take a dose of hydroxychloroquine and/or azithromycin to prevent COVID-19?

No. Definitely not.

Q: I sometimes take ibuprofen (Advil) for pain. Is it true that taking ibuprofen can make COVID-19 symptoms worse?

Per Health Canada, there is currently no scientific evidence to suggest that ibuprofen worsens the effects of the COVID-19. There is no association between non-steroidal anti-inflammatory drugs (NSAIDs) and COVID complications. However, you should still follow any guidelines specific to your neuromuscular disorder (e.g., people with Duchenne Muscular Dystrophy should not take ibuprofen, regardless of the presence of a viral infection).

Q: My son has Duchenne Muscular Dystrophy. He started on Cortizone (Deflazacort and Prednisone) about 2 months ago. Is Cortizone putting him at higher risk?

We do not have specific experience on whether steroid use worsens COVID-19 related disease. However, we believe it is likely that any medication that suppresses the immune system may put people at higher risk from viral infections. A recent systematic review suggests that there is higher risk from corticosteroid use with influenza infection. Overall, the risks and benefits of treatment need to be considered, and this doesn't mean it is a bad idea to be on corticosteroids.

Q: Should I cancel my clinical trial visit appointment at the hospital? Will I be removed from the trial if I don't go to the hospital?

If you or your child are a participant in an active clinical trial and you have a trial visit coming up, please contact the investigator and/or the study coordinator at your trial site. Ask whether the visit is going ahead and what other changes to the protocol may be required in the current situation. Ask whether study visits are as planned, have been cancelled, postponed, or changed in any other way such as being replaced by a phone call or telemedicine visit. This might be different from trial to trial and site to site, but the safety of participants is always top priority.

Q: For those with neuromuscular disorders taking steroids, are they at an increased risk of contracting COVID-19? Should we stop taking steroids?

NO. Do not stop taking steroids, as it can be more dangerous to suddenly stop taking steroids. Patients on steroids should continue taking them.

Q: I receive my medications and medical supplies by mail from my pharmacy. What should I do to ensure I do not contract COVID-19 from these packages?

Receiving your medication through the mail from the pharmacy is probably the least risky way to get infected. If you are concerned, you may wipe the surface of the package before opening with water and soap or disinfectant.

QUESTIONS ABOUT WORK/SCHOOL OUTSIDE THE HOME

Q: My child has a neuromuscular disorder and I am an essential worker. What should I do to protect my child as I leave and enter our home for work each day?

Depending on the nature of your work there may be precautions you can take to reduce your chance of becoming infected. At home, there are also precautions you can take to reduce risk of transmitting infections. Mainly, these consist of good handwashing practises, frequent hand washing, coughing or sneezing into your elbows. Wherever possible, observing distance, avoidance of sharing utensils/glasses, using separate washrooms, and frequent cleaning of high-use surfaces would all reduce risks. If you believe the number of interactions with other, potentially infectious people is relatively high, you could also do the following:

- Put a clothes hamper lined with a garbage bag just inside the home's entrance. Clothes worn outside which may have come in contact with the virus should

- be placed inside the garbage bag. Throw them directly in the wash (on hot or warm) if you can.
- Shoes can be placed in another garbage bag or left outside the home if possible.
- Clean keys, cell phones and other items you've been carrying with disinfecting wipes or water and soap.
- Door handles and light switches near the entrance should also be disinfected.
- Shower immediately upon returning home from work

Q: My daughter attends university. Her classes are cancelled for now but she is planning on taking summer classes. If classes resume in-person in the summer, should she still practice physical distancing and take classes remotely.

This will need to be assessed a bit closer to the time.

QUESTIONS ABOUT MEDICAL APPOINTMENTS

Q: My child has Spinal Muscular Atrophy and receives Spinraza. Our physiotherapist suggests that because of COVID-19, we continue PT sessions online. Will this work?

Give it a try, probably the best option for the time being to continue some type of physiotherapy while keeping the infection risk low. In fact, there are a wide array of remote rehabilitation—or telerehab—options, ranging from high-tech, interactive systems to video-chat sessions with individual physical therapists to app-based programs. There is scientific evidence to show certain telerehab physical therapy programs are just as effective as in-person therapy.

Q: My son has Duchenne Muscular Dystrophy. If he were to contract COVID-19, would he not be prioritized for a ventilator or ICU stay because he has a terminal illness compared to an otherwise healthy person with COVID-19? Will he be 'black carded'?

No. There is no such policy at Canadian hospitals. Medical teams always try to provide the best possible treatment for their patients, weighing the benefits and harms from any possible intervention for an individual case. Having a terminal disease does not prevent someone from receiving treatment for a different condition.

Q: I am an adult with Becker Muscular Dystrophy. I have an appointment in clinic at the hospital in 2 days and I am nervous to go. Should I stay home?

Many hospitals need to prioritize urgent appointments or have restrictions, who can have access to the hospital. Many departments now also offer telemedicine appointments. Check with your clinic to see what they can suggest.

Q: I am an adult with Spinal Muscular Atrophy. I have an appointment at the hospital. It has not been cancelled but I was told that in order to ensure the safety of patients and staff, there will be no visitors permitted, including family members or companions accompanying patients to appointments or

procedures. I need someone to come with me to all of my appointments.
What should I do? *Ignited by passion, fueled by hope.*

Contact the clinic prior to your appointment and let them know you require someone to accompany you to your appointment. A formal caregiver who provides critical supports is permitted to accompany a patient to clinic appointments at most hospitals. If you require further support or help with navigating this situation, you can contact your MDC Service Specialist for support.

QUESTIONS ABOUT COVID-19

Q: How long can COVID-19 live on surfaces outside of the body?

According to a recent study, viable COVID-19 virus could be detected up to 4 hours on copper, up to 24 hours on cardboard, and up to 2-3 days on plastic and stainless steel (van Doremalen et al. NEJM. 2020).

Q: How common is it for someone with a neuromuscular disorder to get the common/seasonal flu?

The likelihood is probably very similar to the general population, but depends on your occupation, number of social contacts, exposure risk etc. The flu vaccine is recommended for people with neuromuscular disorders.

Q: What is testing for COVID-19 like?

A swab is used to collect nasal fluids that may contain the virus. As a virus contains genetic material, the method for detecting the virus by PCR (polymerase chain reaction) is to determine if this viral genetic material is present.

Q: What financial supports exist?

Federal and provincial governments are rolling out a wide range of financial support measures to best support Canadian communities, businesses, families and individuals who have been impacted by the COVID-19 pandemic, please visit:

- [Canada's COVID-19 Economic Response Plan for INDIVIDUALS & FAMILIES](#)
- [Canada's COVID-19 Economic Response Plan for BUSINESSES](#)

In addition to new supports being introduced as a result of COVID-19, you may also want to learn more about previously existing government and community supports. Specifically, to learn more about disability benefits programs offered at federal, provincial, and territorial levels of government, please visit the Government of Canada's [Disability Benefits site](#).

To learn more about community resources available in your specific community, please visit Canada 211, Canada's primary source of information on government and community-based health and social services, at 211.ca, or call 2-1-1 from your phone (where service is available).

Please also feel free to contact your MDC Service Specialist to help with navigating these different resources and supports.



Ignited by passion, fueled by hope.

For more information, please visit www.muscle.ca, www.neuromuscularnetwork.ca OR if you have any questions please email research@muscle.ca