

Coronovirus (COVID-19) and Mitochondrial Disease Frequently Asked Questions

Mitochondrial disease is a group of disorders of which there are currently over 300 illnesses associated. As there is such a wide range of disorders, with widely varying levels of symptoms and disability, it is difficult to make specific recommendations that apply.

The following recommendations apply to numerous mitochondrial disorders, and are general in nature. These recommendations are designed primarily for patients, and caregivers, but do not replace the advice of your physicians. We recommend that all mitochondrial disease patients and caregivers consult with their health care provider for any question relating to the health and wellbeing of a mitochondrial disease patient.

Please note that this is a changing situation, and that information from the experts is being updated on a daily basis. Please refer to your physician and public health authority for the latest updates.

What is Coronovirus

What is Coronavirus (COVID-19)?

Coronavirus disease (COVID-19) is an infectious disease caused by a newly discovered coronavirus. Most people infected with the COVID-19 virus will experience mild to moderate respiratory illness and recover without requiring special treatment. Older people, and those with underlying medical problems like cardiovascular disease, diabetes, chronic respiratory disease, and cancer are more likely to develop serious illness.

The best way to prevent and slow down transmission is to be well informed about the COVID-19 virus, the disease it causes, and how it spreads. Protect yourself and others from infection by washing your hands or using an alcohol based rub frequently and not touching your face.

The COVID-19 virus spreads primarily through droplets of saliva or discharge from the nose when an infected person coughs or sneezes, so it is important that you also practice good respiratory hygene (for example, by coughing into a flexed elbow).

At this time, there are no specific vaccines or treatments for COVID-19. However, there are many ongoing clinical trials evaluating potential treatments. The World Health Organization continues to provide updated information as soon as clinical findings become available.

(source: World Health Organization)



What are the symptoms of COVID-19?

Those who are infected with COVID-19 may have little to no symptoms. You may not know you have symptoms of COVID-19 because they are similar to a cold or flu. Symptoms have included:

- cough
- fever
- difficulty breathing
- pneumonia in both lungs

In severe cases, infection can lead to death.

Symptoms may take up to 14 days to appear after exposure to COVID-19. This is the longest known incubation period for this disease.

Recent evidence indicates that the virus can be transmitted to others from someone who is infected but not showing symptoms. This includes people who:

- have not yet developed symptoms (pre-symptomatic)
- never develop symptoms (asymptomatic)

While experts know that these kinds of transmissions are happening among those in close contact or in close physical settings, it is not known to what extent. This means it is extremely important to follow the proven <u>preventative measures</u>.

(source: Public Health Agency of Canada)

How do we know the difference between the regular flu, seasonal allergies, and the coronavirus? It is not possible to know the difference without testing for the COVID-19 virus. If you are experiencing any of the <u>symptoms listed above</u>, please contact your provincial/territorial health service to receive directions.

It is critical that if an individual is experiencing symptoms to immediately self-isolate and contact your public health authority. (source: <u>Public Health Agency of Canada</u>)

MitoCanada has published a province-by-province breakdown of who to call if you think you, a patient or a caregiver might have Coronovirus (COVID-19). That list can be found on our website at: <u>https://mitocanada.org/covid19_provincial_information/</u>.

Risks to Mitochondrial Disease Patients

Does the coronavirus put a mitochondrial disease patient at a higher risk, or does risk depend on the severity of the disease in the patient?

The severity of COVID-19 is difficult to predict in different people. In general, if one's health is not good because of various reasons, then tolerance of any type of infection is more difficult, but it is not possible to predict if someone contracts COVID-19, how severe the disease will be.

We hear that children are less impacted by the coronavirus. How does that affect children with mitochondrial disease?

There is no data that we know of that indicates that children are more resistant, as there is no data on how many children have been infected.



What's the risk to a patient when someone goes out of the house and into public spaces (example: the grocery store)?

The best way to protect a mitochondrial disease patient in the home, is to not bring the virus into the environment, and practice disease prevention protocols. Please refer to our disease prevention protocol list in the <u>Disease Prevention section</u> of this FAQ.

Some mitochondrial disease patients are taking mast cell stabilizers or large doses of antihistamines, can taking these medications make you more susceptible to contracting Covid-19 or make an infection to Covid-19 more severe because of these medications?

We do not have any data that suggests that just taking these medication increases risk. Exposure to the virus increases risk of contracting COVID-19, and the severity is uniquely based on the individual.

Disease Prevention

Is there anything a patient or caregiver can do or take to prevent the coronavirus in mito patients?

The best way to protect a mitochondrial disease patient in the home, is to not bring the virus into the environment, and practice disease prevention protocols.

Disease prevention from the <u>Public Health Agency of Canada</u>:

- wash your hands often with soap and water for at least 20 seconds, especially after using the washroom and when preparing food
 - o use alcohol-based hand sanitizer if soap and water are not available
 - when coughing or sneezing:
 - o cough or sneeze into a tissue or the bend of your arm, not your hand
- dispose of any tissues you have used as soon as possible in a lined waste basket and wash your hands afterwards
- avoid touching your eyes, nose, or mouth with unwashed hands
- stay at home unless you have to go to work
 - talk to your employer about working at home if possible
- avoid all non-essential trips in your community
- do not gather in groups
- limit contact with people at higher risk, such as older adults and those in poor health
- go outside to exercise but stay close to home
- if you leave your home, always keep a distance of at least 2 arms lengths (approximately 2 metres) from others
- if you leave your home, wear a face mask
- household contacts (people you live with) do not need to distance from each other unless they are sick or have travelled in the last 14 days

Additional recommendations to protect mitochondrial patients:

- if you have come in from outside, have a shower and change into clean clothing, and wash the outfit you wore outside
- wipe down any items that have come in from outside with a cleaning cloth (example: Clorox cleaning wipes), and leave in cupboard for two days before using
- wash fruits and vegetables before eating
- peel any fruits/vegetables (after thoroughly washing your hands) before giving to the mitochondrial disease patient, to avoid them touching the exterior of the fruit



Mitochondrial Disease Patient Care

What are items that mitochondrial disease patients and caregivers keep on hand?

MitoCanada has developed a Coronavirus (COVID-19) Readiness Checklist for patients and caregivers. The checklist can be found on our website at: <u>https://mitocanada.org/wp-content/uploads/2020/03/COVID-19-Readiness-List-1.pdf</u>.

Should doctor's appointments be kept?

Scheduled visits should be attempted via teleconference where possible, and if not urgent, should be cancelled. Contact your health care provider to see if telehealth is available.

What about exercise? Should that continue and can it be vigorous?

Yes, it is fine to continue your exercise program. Exercise is good for both mitochondrial health and for anxiety. When exercising outside, practice physical distancing, avoiding any pathways with large amounts of people.

How does a patient or caregiver distinguish between symptoms of coronavirus or symptoms of a mito flare up?

It is not possible to know the difference without testing for the COVID-19 virus. If you are experiencing any of the <u>symptoms listed above</u>, please contact your provincial/territorial health service to receive directions.

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When should a mitochondrial disease patient visit the emergency room?

It is important that you discuss with your physician how to make the decision as to when a visit to the emergency room is needed. The choice to go to the emergency room is not one that people take lightly, and mitochondrial disease patients and caregivers should continue to use the same decision-making process that they have previously used to make this decision.

Should mitochondrial patients give the same protocol to emergency room physicians that we already have for instruction in times of sickness, or is there additional information we need to give? As every visit to the emergency room is unique. There is no specific protocol that individuals should follow. Please follow the same emergency room visit protocol you have discussed with your physician.

If a mitochondrial disease patient is experiencing increased anxiety during this time, does this increase their needs for fluids?

No, stress and anxiety does not change an individual's need for fluids.



Is it safe for home health aides to come to the house? What if they request a trainee accompany?

Professional home health aides should have knowledge of and be following the rigorous guidelines set out by their public health authority, so allowing those individuals into the home is ok. We do not recommend you approve the request of having a trainee accompany them at this time.

Any professional home health aide should be:

- washing their hands when they arrive
- wearing a face mask

We recommend that, if possible, the patient also wear a face mask during home health aide visits.

Steps to take if a patient was exposed or thinks they may have been exposed?

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What should a parent or caregiver do should a patient contract the corona virus?

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How important is the mito cocktail in case a mito patient ends up in intensive care for COVID? Especially with shortages on drugs, meds and supplies?

The mito cocktail has a long half-life and is stored in the body for a long time. There should not be an issue if a patient was not on the mito cocktail for several weeks. An individual can resume taking the mito cocktail once they start recovery from COVID-19.

Should patients increase the Mito Cocktail dosages?

There is no evidence to suggest increasing the Mito Cocktail dosage will reduce symptoms if infected by COVID-19. Please consult your primary mitochondrial disease physician if you have more specific questions about your cocktail dosage.

