

COVID-19 and Dystonia: Your Questions Answered

DMRF and DMRF Canada hosted a webinar on Dystonia and the COVID-19 Virus - Your Questions Answered on Wednesday, April 1, 2020.

Movement Disorder Specialists Mark Hallett, MD of the National Institute of Neurological Disorders & Stroke, [and Dr. Robert Chen, of the Toronto Western Hospital and the University of Toronto](#), addressed questions from the dystonia community about the COVID-19/coronavirus. The dystonia community is grateful to Drs. Hallett and Chen for their valuable input in this area.

Below is an overview of that discussion, with thanks to Dr. Robert Chen for summarizing for those of you who were not able to participate in the webinar or cannot review the recording.

A reminder that every dystonia case is different. We strongly recommend that you speak with your doctor if you have any questions or concerns regarding your specific case.

Question: Does having dystonia, any form of dystonia, put a person at high risk for COVID-19?

Dr. Chen clarified that there is no data that suggests that individuals affected with dystonia have a higher risk of getting COVID-19 than individuals who are not affected by it.

In terms of adding complications to dystonia, it depends on the type of dystonia the individual is affected with. For example, if someone has a form of dystonia where only the arm, the eye or the neck is affected then that really shouldn't put the individual at higher-risk than the general population of getting complications from Covid-19. However, if someone has dystonia that affects swallowing, breathing or mobility, then that may put the person at higher risk of getting complications from COVID-19.

Question: Why does the Centres for Disease Prevention and Control (CDC) list, “Neurological and neurologic and neurodevelopment conditions” under “Underlying medical conditions that may increase the risk of serious COVID-19 for individuals at any age”?

Dr. Chen states that if a dystonia patient has difficulty breathing or swallowing then they may be more prone to developing complications. However, having dystonia by itself would not increase the risk of getting COVID-19 but perhaps in some cases, it may predispose to higher risk of developing further complications.

Question: Are there special precautions someone with dystonia should take? What would they be?

Dr. Chen confirmed that there are no special precautions that are necessary to be taken. The precautions that should already be taken is handwashing and basically following the general advice that has already been provided through the Government of Canada website [and available here](#).

Question: Many people are experiencing or anticipating delays in their scheduled botulinum neurotoxin injections. This is creating anxiety – what suggestions do you have for how they can mitigate their dystonia symptoms?

In certain clinics, patients who have appointments for their injections are being contacted to have a discussion with their physicians and a lot of patients are choosing to delay the administration of their injections. However, there are exceptions being made for patients who have significant problems and require immediate medical assistance. Patients are encouraged to contact their injectors to discuss options such as timing of the next injections and possible changes to medications.

Anxiety could worsen the symptoms of dystonia. Dr. Chen suggests if you are feeling anxious, it's best to contact the provider or the neurologist; you could speak via telephone or video conference. If necessary, they may be able to adjust the medication. Your specialist would know the best course of action to take treating you better.

Question: Some people in some areas still have their appointments. They want to know if it is safe for them to get their botulinum neurotoxin injections currently. Will the injections make them more prone to getting sick from the virus? Any concern about receiving injections in the head, neck and vocal cords? Is it worth going out of the house for treatment?

According to Dr. Chen, there is no evidence so far that would suggest the administration of botulinum neurotoxin injection at this time would more likely get people sick from the virus.

As for going out of the house for treatment, one should analyze the risk-benefit ratio; going to the clinic would mean you are putting yourself at risk of getting COVID-19. However, the actual injection itself is unlikely to give people a high risk of getting the virus.

Question: Does having had DBS make you more prone to getting the COVID-19 virus?

There is no evidence that DBS would make one more prone to getting the COVID-19 virus. DBS does not compromise the immune system. However, patients who have recently undergone DBS surgery may need to take extra precautions.

Question: If someone was scheduled to have their DBS batteries replaced and now have been told this is an elective procedure – do you have advise on what they should do help reduce their symptoms if the symptoms return? Should they be worried that their batteries would run out of power completely?

Dr. Chen confirmed that in most cases, battery replacement is scheduled some time in advance of when they would run out and the DBS system stop working. In those cases, delaying it by one or two months it shouldn't affect the patient. The most important thing would be for a dystonia patient to contact their DBS team directly regarding specific questions. The DBS team will know what the status of the battery is. The situation is different for everyone, and in some cases the program parameters may be adjusted to reduce the power consumption if needed. Most centres will consider battery replacement an essential procedure if battery failure is imminent. Again, it's best to contact an individual's DBS team for more information.

Question: Do any of the other medications commonly used to treat dystonia like Artane®, baclofen, or Sinemet or Tetrabenazine make a person more vulnerable to getting the virus?

According to Dr Chen, none of these medications would cause problems that would in turn increase the risk of contracting the virus.

Question: Are there special precautions someone with DBS should take to avoid getting the virus?

There are no special precautions for someone with DBS to take to avoid getting the virus except following the general advise about social distancing, handwashing, avoid touching their face. [We encourage all dystonia patients to refer to the following website for updates from public health here.](#)

Question 12 - Many people are very anxious about the current situation and the anxiety and fear is making their dystonia worse. Do you have advice for how to cope in these days of uncertainty?

Dr. Chen advises patients consider the following: create a schedule of the tasks you do daily; exercising at home using online material; keeping in touch with your doctors and if there is a possibility, going out for walks within your area.

DMRF Canada has included some other suggestions [here](#).

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