I have a neuromuscular disorder*, should I get a vaccine for COVID-19?

In general, yes. Most people with neuromuscular disorders (NMD) should receive the vaccine and it should protect them from the COVID-19 virus.

Clinical trial results show that COVID-19 vaccines are safe and highly effective. The side effects, for the most part, are temporary and unpleasant, but not dangerous. We do not expect the side effects to be any different for people with NMDs from everyone else.

To our knowledge, people with NMDs were not part of those clinical trials, so we don't know how well these vaccines work. This is especially true for people with NMDs that are on an immunosuppressant/immunosuppressed. However, we do know that the risk of COVID-19 infections likely outweighs the potential risks of the vaccine.

Muscular Dystrophy Canada has designed this pamphlet to help you decide with your neuromuscular specialist which option is best for you.

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*This decision aid is for you if you are an adult (age >18 years) and have a neuromuscular disorder or a parent of a child (age >16 years) who has a neuromuscular disorder. A neuromuscular disorder includes, but is not limited to, the following conditions: (1) Muscular Dystrophies; (2) Congenital Muscular Dystrophies; (3) Congenital Myopathies; (4) Auto-immune Mediated Myopathies; (5) Metabolic Myopathies; (6) Genetic and Immune-Mediated Neuromuscular Junction Disorders; (7) Hereditary Peripheral Nerve Disorders (Genetic Neuropathies; (8) Immune-Mediated Peripheral Nerve Disorders and; (9) SMA and related lower motor neutron disorders.

How do vaccines work?

All vaccines work by training your immune system to respond to an infection. They do this in different ways. The two Health Canada approved vaccines (Pfizer-BioNTech and Moderna) use messenger RNA (mRNA) technology.

To understand how a mRNA-based vaccine works, let's first review how a virus works: a virus contains genetic materials composed of DNA or RNA. To build what it needs, the virus will make mRNA - this is a genetic recipe for making a piece of the spikes that sit atop the coronavirus.

The mRNA reads and translates information out of the nucleus into specific proteins and structures. The mRNA vaccine contains a mRNA coding for a critical piece of the virus. In the case of the COVID-19 vaccines, it’s a spike protein located on the virus’ outside coat.

Your immune system will learn to attack this spike protein produced from the mRNA vaccine.

Basically, when the vaccinated person comes into contact with the virus, the immune system will recognize the spike protein and launch a rapid and effective attack to get rid of the infection so you do not become sick.

These vaccines do not contain live COVID-19 virus, so there is no chance of getting COVID-19 from them.

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What are the benefits of the COVID-19 vaccine?

Preventing COVID-19 infection. These vaccines prevent up to 95% of COVID-19 infections in people who get the vaccines.

Reducing severity of COVID-19. COVID-19 is less severe in people who get the vaccine.

Protecting others. Getting vaccinated yourself may also protect people around you. As more people get vaccinated, we will see less COVID-19 spread.

What are the side effects of the COVID-19 vaccine?

Side effects may vary from person to person. **The side effects reported are not dangerous and are temporary (wear off within a day or so).** The most common side effect is a sore arm where the injection was given. Other reported side effects are temporarily swollen arm pit lymph nodes, tiredness, fever, chills, headache, general muscle or joint pain.

Side effects from the second dose can be more noticeable because your immune system is now trained to recognize the part of the COVID-19 virus that is being delivered by the vaccine.

What should I do with my therapies and treatments if I get the vaccine?

If you are receiving treatment with Intravenous immunoglobulin (IVIg) or other immune suppressing medication, you should discuss your case with your treating physician. You should also discuss vaccination timing with your specialist.

The currently approved vaccines are compatible with gene and RNA therapies. Some gene therapies are based on adeno-associated viruses (AAV), but that is a different virus that shares little similarity with coronavirus or the vaccines.

Some vaccines (Astra Zeneca and others) use adenovirus, but this a completely different virus from AAV despite the similar name.

If you are involved in a clinical trial, you should discuss the vaccine with the study team, to determine whether/when a vaccine is permitted.

While we do not not yet have information on specific medications and the COVID-19 vaccine, we know from other vaccines that some medications (e.g., rituximab for Myasthenia Gravis) may reduce the protection you receive from the vaccine, although most people are still protected.

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Who should be prioritized for the vaccine?

The reason for some people getting the vaccine before others is to try and prevent the most vulnerable people from getting COVID-19. This includes people who would likely get very sick if they were infected. Even though clinical observations have noted people with Myasthenia Gravis and Myotonic Dystrophy are at particular high risk for COVID-19, we do not have the data to say one type of NMD is at higher risk than others. Not all persons with NMDs are in a highly vulnerable situation. Some factors that could put a person with a NMD at higher risk include:

- Taking medications that suppresses the immune system (e.g., deflazocort)
- Respiratory complications (e.g., using a ventilator)
- A weak cough
- Cardiac complications
- At risk of deteriorating or developing rhabdomyolysis during fever, fasting or infections
- Requiring multiple caregiver supports

In other words, people considered at high risk for COVID-19 are people with severe or unstable respiratory compromise; reliance on home ventilation; clinically relevant impairment of heart function; immunosuppression; severe weakness requiring multiple caregivers or complex ongoing support in the home, community or institutional setting.

What are my choices?

1. Have the vaccine when offered and available to you.
2. Wait for more information.

Regardless of your choice, it is important to continue to follow public health measures and not assume you are completely protected from COVID-19.

Helpful NMD-Specific Resources

Doctor – Should I get the COVID-19 vaccine? Infection and Immunization in Individuals with Neuromuscular Disorders

No Excess Risk for Neurologic Events Observed to Date from COVID-19 Vaccines

World Muscle Society Advice on Vaccines

Ask the Experts About COVID-19 & NMDs

Ask the Experts About COVID-19 Vaccines & NMDs

Please note that the information in this decision aid reflects the general knowledge of the field at the date of publication. Muscular Dystrophy Canada accepts no responsibility or liability whatsoever for any errors or omissions.

If you are pregnant or breast-feeding, additional considerations apply. Speak to your healthcare provider for more information.

Content Contributors:
Dr. Reshma Amin
Dr. Erin Beattie
Dr. Megan Bettle
Dr. Valérie Gagné-Ouellet
Dr. Hans Katzberg
Dr. Rashmi Kothary
Dr. Anne Pham-Huy
Dr. Gerald Pfeffer
Ms. Stacey Lintern
Dr. Hanns Lochmuller
Dr. Allison McGeer
Dr. Colleen O'Connell
Dr. Homira Osman
Dr. Rachel Thompson
Dr. Jodi Warman Chardon
Dr. Toshifumi Yokota

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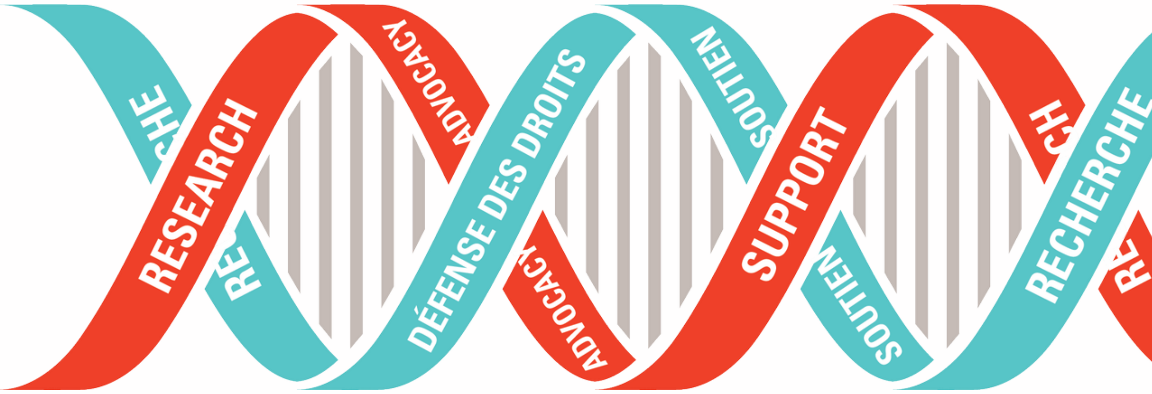
This decision aid was adapted with permission from the Canadian Rheumatology Association and Canadian Arthritis Patient Alliance. Decision Aid for the COVID-19 Vaccine in Patients with Autoimmune Rheumatic Diseases.

MISSION

Muscular Dystrophy Canada's mission is to *enhance the lives* of those affected with neuromuscular disorders by continually working to provide ongoing support and resources while relentlessly searching for a cure through *well-funded research.*



MDC is ready to support you with the 'here and now' and the future

MDC is a not-for-profit registered charity with Imagine Canada Standard accreditation. Our vision is to find a cure for neuromuscular disorders in our lifetime. We invest in innovative research and work with researchers and clinicians across the country to move research forward so treatments, and ultimately a cure, can be found for NMDs. At the same time, we provide critical services such as *system navigation, education, funding for life-changing equipment and assistive technologies, peer and well-being supports, and influence positive change with our advocacy initiatives.

MDC is also proud to be a funder and partner of the new pan-Canadian network of neuromuscular disorders stakeholders - NMD4C. Together we would like bring together the country's leading clinical, scientific, technical, and lived expertise to improve care, research, and collaboration.

Whether you or a family member is personally affected by a neuromuscular disorder or you are a supporter, donor, Fire Fighter, health care professional, researcher, volunteer or industry partner, we thank you for the support in helping us to deliver our mission and we welcome you to connect with us!

*Our Systems Navigation program is designed to support clients in all areas of their non-medical needs including: funding equipment to improve daily life, providing emotional and educational support, and ensuring access to vital resources and support systems. If you need support, please contact your Service Specialist.

If you have a research or disorder related question, please contact the Research Hotline - call 1 800 567-2873 ext. 9037 or email research@muscle.ca.

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1-800-567-2873

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