Information for people with neuromuscular, neurologic, or muscle conditions who use respiratory supports

March 19, 2021

Why is planning for a COVID-19 vaccine important?

- People may need respiratory support, such as a ventilator or BiPAP, due to weakness caused by neuromuscular conditions affecting the brain, motor nerves, spinal cord, or muscles. Conditions that can sometimes require respiratory support include ALS, Spinal Muscular Atrophy, Muscular Dystrophies, spinal cord injury, and many other myopathies and neuropathies.
- If this applies to you, there may be both logistical and health related things to think about and plan for.
- It is very important that you monitor how you are feeling in the days leading up to your vaccine appointment. If you are feeling sick, rebook for when you are feeling better.

Should I get the COVID-19 vaccine? Will the vaccine work for me?

- All of the COVID-19 vaccines available in Canada are safe, and they do not contain any live virus. The vaccines cannot give you COVID-19.
- Doctors and researchers have looked at the evidence. They agree that unless you have a very serious allergy to any of the vaccine ingredients, you should strongly consider getting the COVID-19 vaccine because you have a higher chance of experiencing severe symptoms if you get COVID-19 due to the weakened muscles around your lungs.
- While people with neuromuscular conditions were not specifically included in the clinical trials of the COVID-19 vaccines, some people with lung disease and a small amount of people with arm and leg weakness were included. The vaccine was not found to be any less safe or effective for them.
- The way the vaccines work means that there is a strong chance that your immune system will learn to protect you from COVID-19.
What about the medications or treatments that I take?

- If you are taking immunosuppressant medications (such as deflazacort or prednisone), you can also read the information sheet on autoimmune neuromuscular conditions treated with immunosuppressant therapy on the BCCDC website.
- If you don’t see your medication listed, or if you take medications for another condition and you aren’t sure if you need to worry about timing, you can also look at the COVID-19 vaccine planning considerations posted on the BCCDC website for that condition (if available), and/or call 8-1-1 or talk to your health-care provider.

How else should I plan for my vaccine appointment?

- Review HealthLink BC’s general information on COVID-19 vaccines.
- In the 2-3 days leading up to your vaccine monitor yourself: are any of the typical symptoms of your condition new or getting worse? If you aren’t feeling well, rebook your vaccine appointment for another day. You won’t lose your place in line. Consider reaching out to your health care provider about your worsening symptoms.
- You can feel safe going to a COVID-19 vaccination location, as they are following all COVID-19 safety precautions. If you receive home health care services, you may be able to receive your vaccine at home.
- Some people with neuromuscular conditions don’t have a lot of muscle mass in the upper arm. If this applies to you, you can ask to have your vaccine injected into your upper leg instead.

What or who should I bring with me?

- Please bring your BC Services Card or CareCard to your appointment.
- You can bring any medical or mobility equipment that you need.
- If you need to, you can bring a trusted friend, family member or caregiver with you to support you through the process and/or translate for you as needed. Please only bring one person.
What happens after my vaccine?

- Everyone who gets a COVID-19 vaccine will stay on location to be monitored for 15 minutes after they receive their vaccine.
- You should tell a health-care provider at the vaccination site if you do not feel well.
- If you have any new or worsening symptoms once you go home, please call your health care team or 8-1-1. If you have a severe allergic reaction, call 9-1-1 immediately.
- Everyone will have to continue following COVID-19 safe practices for a while, even after getting their vaccine. You can learn more about what to expect after your vaccine on the BCCDC website.

My vaccine planning checklist

☐ Read the COVID-19 vaccine information for my condition(s)

☐ Time my vaccine appointment around my medication and treatments (if relevant to me)

☐ Talk to my doctor if I have any questions or need any help planning my medication

☐ Monitor how I’m feeling leading up to my vaccination appointment. Is anything new or getting worse compared to how I usually feel?

☐ Make sure I am feeling my usual self on the day of my vaccine appointment

☐ Plan to bring the medical and mobility equipment I need with me