

Planning for your COVID-19 vaccine

Information for people with paroxysmal nocturnal hemoglobinuria (PNH)

November 23, 2022

Why is planning for a COVID-19 vaccine important?

- Some people with PNH may need to time their vaccine around their medications and treatments.
- It is also important that you monitor how you are feeling in the days leading up to your vaccine appointment. If you do not feel well, 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. Vaccines teach your body to develop antibodies against the COVID-19 virus. These antibodies will help fight off future infections and protect from serious illness.
- 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. This is because you have a higher chance of experiencing severe symptoms if you get COVID-19. Viruses like COVID-19 can also cause your PNH to get worse.
- People with PNH weren't included in the clinical trials of the COVID-19 vaccine. However, 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 if I test positive for COVID-19?

- If you've recently had a positive COVID-19 test result, you can wait up to 3 months for a booster dose. The likelihood of a COVID-19 reinfection during this period of time is small because having COVID-19 boosts your immunity.
- You can also choose to get a booster dose at any time after your symptoms have passed. It is not harmful to get vaccinated and it will give you a good boost to your protection.

Planning for your COVID-19 vaccine

What about the medications or treatments that I take?

- If you are taking **eculizumab**, it is important to book your vaccine **one-two days before or one-two days after** your eculizumab dose.
- This is **important for your safety**. Timing your vaccine around your eculizumab dose reduces your chance of having a flare up of your PNH symptoms.
- 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 your typical symptoms new or getting worse?
- If you receive the COVID-19 vaccine on a day you are feeling unwell, you could experience a flare up of your condition which could be serious. 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.
- Some people with PNH take blood thinners or have low platelets, so if this applies to you, you can ask for extra pressure applied to your arm after you get the vaccine to reduce bruising.
- You can feel safe going to the COVID-19 vaccine clinic, as they are following all COVID-19 safety precautions.

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 if needed. Please only bring one person.

Planning for your COVID-19 vaccine

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.
- If you take blood thinners or if you have low platelets, you will need to apply extra pressure to your arm for 3-5 minutes after you get your vaccine to reduce bruising.
- 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.
- 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?
- Plan to bring the medical and mobility equipment I need with me