

Information for people who have Atypical Hemolytic Uremic Syndrome (aHUS)

March 19, 2021

Why is planning for a COVID-19 vaccine important?

- Preparing for your vaccine is important, because some people with aHUS may need to time their vaccine with their treatment infusions.
- It is very 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 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. This is because you have a higher chance of experiencing severe symptoms if you get COVID-19. Viral infections like COVID-19 can also cause your aHUS to get worse.
- People with aHUS weren't included in the clinical trials of the COVID-19 vaccines. While the COVID-19 vaccines are very safe, we do not know exactly how much protection they will give people with aHUS compared to those who do not have aHUS.
- However, the way the vaccine works 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 **eculizumab**, it is important to book your vaccine **either in the day or two before, or the day or two after** your eculizumab dose.
- Timing your vaccine close to your eculizumab dose reduces the chance of having a flare up of your aHUS symptoms.
- If you take medications for another condition and you aren't sure if you need to consider 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](#).
- It is very important that you are feeling as well as possible when you get your vaccine.
- In the 2-3 days leading up to your vaccine monitor yourself: are any of your typical symptoms new or worsening? If you receive the COVID-19 vaccine on a day you are not feeling well, you could experience a flare-up of your condition. 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.
- Is there anything about your health condition that the person giving you your vaccination should know? For example:
 - People with aHUS sometimes take blood thinners as part of their care. If this applies to you, you may want to ask for extra pressure applied to your arm after you get the vaccine to reduce bruising.
 - Many people with aHUS also receive dialysis. If this applies to you and you have a dialysis fistula on one of your arms, you can ask the vaccinator give you the vaccine in your other arm.

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.

What happens after my vaccine?

- Everyone who gets a COVID-19 vaccine will stay on location to be monitored for 15 minutes after they get their vaccine.
- If you take blood thinners, you can reduce bruising by applying extra pressure to your arm for 3-5 minutes after you get your 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