I have an autoimmune rheumatic disease*, should I get a vaccine for COVID-19?

Clinical trial results show that COVID-19 vaccines are safe and effective in the general population. However, people with autoimmune rheumatic diseases were not part of those clinical trials, so we don’t know how well these vaccines work in people with autoimmune rheumatic diseases. We do know with other vaccines, like the flu shot, people whose immune system activity is lowered by medications may have somewhat less protection from vaccination, although most people are usually still protected.

Should I get vaccinated now, or wait?

The Canadian Rheumatology Association has designed this pamphlet to help you decide with your healthcare provider which option is best for you.

*This decision tool is for you if you are an adult (age >18 years) or a child aged 12 years or older and have an autoimmune rheumatic disease, which includes (but is not limited to) the following conditions: Ankylosing spondylitis/spondyloarthritis, Autoinflammatory disease, Behcet’s disease, Juvenile idiopathic arthritis, Myositis, Polymyalgia rheumatica, Psoriatic arthritis, Reactive arthritis, Relapsing polychondritis, Rheumatoid arthritis, Scleroderma, Sjogren’s syndrome, Systemic Juvenile Idiopathic Arthritis, Still’s disease, Systemic lupus erythematosus, Vasculitis.
How do the COVID-19 vaccines work?

All vaccines work by training your immune system to respond to an infection. They do this in different ways. Some, including the flu shot and COVID-19 vaccines in development, use a small, dead piece of the virus called a protein.

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

Other vaccines, such as those currently approved for COVID-19, give your cells instructions on how to make this protein. The instructions are delivered using either small pieces of mRNA (mRNA vaccines: Pfizer and Moderna) or through the shell of a different, harmless virus (viral vector vaccines: AstraZeneca and Johnson & Johnson). Your immune system learns to recognize this protein. If you become infected with the virus, your body gets rid of the infection so you do not become sick.

What are the benefits of the COVID-19 vaccine?

1. Preventing COVID-19 infection. These vaccines prevent between 60% to 95% of COVID-19 infections in people who are fully vaccinated. This is even better than the annual flu vaccine, which prevents the flu around 40% to 60% of the time.


3. Protecting others. Getting vaccinated protects you and the people around you. As more people get vaccinated, we will see less COVID-19 spread.
What about side effects or risks?

Like all vaccines, there are some possible temporary side effects or risks of COVID-19 vaccine:

- sore arm where the injection was given
- swollen lymph glands (e.g., in neck or under arm)
- headache
- muscle or joint pain
- fever, chills
- tiredness

These side effects usually wear off within a day or so, but some people can have reactions that last several days and could cause them to miss school, work, or family activities. The side effects from a 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. Side effects vary from person to person.

There is also a very rare risk of a certain type of blood clot that has been linked to the AstraZeneca and Johnson & Johnson vaccines. Information on this is evolving and the latest up to date information can be found on the Health Canada website.²

There is a risk of allergic reactions in those people with allergies to a part of the COVID-19 vaccine, which can be severe. For this reason, you must remain under observation where you get the vaccine for at least 15 minutes after the vaccination (this is also generally the case for all other vaccinations).

More information on allergies to COVID-19 vaccines can be found on the CDC website.³
What you need to know if you have an autoimmune rheumatic disease.

Is the vaccine safe and effective?
We don’t yet know much about the side effects or how well COVID-19 vaccines work in people with autoimmune rheumatic diseases. People with these conditions were mostly excluded from COVID-19 vaccine trials.

However, we do know that other vaccines (e.g., flu vaccines), provide adequate protection for most people with autoimmune conditions, with side effects similar to the general population. Other vaccines do not usually trigger flares of autoimmune conditions. We’ll continue to learn more about this as more people receive the COVID-19 vaccine.

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

The Canadian Rheumatology Association, the Canadian Arthritis Patient Alliance and many other patient and expert groups internationally recommend COVID-19 vaccination for people with autoimmune rheumatic diseases. The Canadian recommendation is available here.

My child has an autoimmune rheumatic disease, should they get the COVID-19 vaccine?
As vaccine eligibility expands, your child may be offered the Pfizer mRNA COVID-19 vaccine. This vaccine was first approved by Health Canada for individuals 16 years or older and has been recently approved for individuals 12 to 15 years of age. In the clinical trials, the Pfizer vaccine was 100% effective at preventing COVID-19 infection in youth 12 to 15 years old and had similar safety to adults.

Your child will be eligible for this vaccine once this age group meets the criteria set by your province. Studies are still ongoing for the younger age groups and with other COVID-19 vaccines.

We urge you to use this tool to discuss the vaccine with your healthcare team. All sections on general considerations in this decision tool also apply to children and youth. Your healthcare team can help you understand the potential benefits and risks of vaccination for your child. Additionally, as a family you can consider getting vaccinated to help protect your child.
Some medications may reduce the protection you receive from the vaccine. While we are beginning to have information on this specific to COVID-19 vaccines, we also have information from other vaccines, which is likely relevant.

Rituximab, mycophenolate mofetil and cyclophosphamide are known to reduce immune responses to vaccines. Other medications may also reduce protection (to a lesser extent) after receiving certain vaccines, although most patients are still protected. If you take a drug like rituximab, you should inform your doctor of your intent to receive a COVID-19 vaccine, as there may be a way to time vaccination to optimize your response, although it is still often better to take the vaccine as soon as it is available to you. For other medications, your healthcare provider can also help you decide what to do with your medications. For many patients, continuing medications is the best option to avoid disease flares.

Your options

1. Have the vaccine now.
2. Wait for more information.

You may choose to have the vaccine now or wait until more information is available. The Canadian Rheumatology Association, the Canadian Arthritis Patient Alliance and many other patient and expert groups internationally recommend you receive the vaccine as soon as it is available.

NOTE: If you choose to receive the vaccine you must still follow public health measures and not assume you are protected completely from COVID-19, just like people without autoimmune conditions.
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References:

CRA Recommendation on COVID-19 Vaccination in Persons with Autoimmune Rheumatic and full manuscript

CRA Position Statement on COVID-19 Vaccination

1 Shared Decision-Making: COVID Vaccination in Pregnancy Decision Aid (produced by a working group at the University of Massachusetts Medical School – Baystate) bit.ly/2LMQUUsn

2 Coronavirus disease (COVID-19) vaccines: Overview bit.ly/3sF6DdG

3 COVID-19 Vaccines and Allergic Reactions bit.ly/2M4Bpf8

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This decision tool, developed by the Canadian Rheumatology Association (CRA) and the Canadian Arthritis Patient Alliance (CAPA), is intended for people with rheumatic disease who are considering COVID-19 vaccination, and is to be used in discussion with your doctor or another member of your healthcare team. Thank you to Cassie + Friends for their review of this guidance for children with inflammatory rheumatic disease.