

Health and wellness decision-making during a pandemic [✗][✓]

Balancing quality of life, safety, individual choice and collective responsibility

Everyone has been faced with difficult decisions during the COVID-19 pandemic. We have had to carefully choose who we interact with, how we interact with them, what risks we feel comfortable taking and what personal sacrifices must be made in order to keep ourselves and our loved ones safe. As public spaces open-up, including schools, we seem to be faced with more of these decisions every day. This will likely intensify as the weather cools across Canada, forcing us to spend more time indoors, and the threat of a second wave emerges.



In this issue of JointHealthTM insight, we provide practical advice for the arthritis patient community on *informed decision making* during a pandemic. We highlight some helpful decision-making tools and consider the risk level of different activities such as visiting a public pool or eating in a restaurant. In this issue, we also provide helpful tips for reducing your exposure to the virus in different situations, including traveling, which a patient may choose to do or may need to do for essential reasons.

**The information provided in this issue is not intended to replace the advice of a healthcare professional or public health official.*

Risk level of different activities

Low risk



Home alone or with household contacts



Outdoors with housemates or social bubble



Outdoors with physical distancing



Outdoor/indoor
Short amount of time



Indoors
Large groups
Long time



Indoors/outdoors
Crowded
Long time

High risk

Should I participate in this activity? Three steps for making an informed decision.

1. Ensure the activity does not go against public health policies in your area

Head to your provincial government's website to find the most up to date COVID-19 policies or guidelines. You should not be doing an activity that goes against the public health response of your region.

Caution: Even if an activity is 'allowed' under your region's COVID-19 policies, it does not necessarily mean that it is safe. Policies are developed based on a number of factors which generally involve balancing the economy with COVID-19 safety, and in some cases, the economy may be more heavily prioritized. In addition, regional guidelines are often developed with the "average" person in mind and therefore may not be well suited for populations who are at higher risk for COVID-19 such as people with arthritis who are immunocompromised. This is what makes step two and step three below particularly important.

2. Determine risk level of the activity

The risk level of an activity will generally depend on the number of COVID-19 cases in your community and the specific setting in which the activity takes place. **Public health** officials in Canada have outlined three settings where exposure to the virus is most likely, including:

- closed spaces with poor ventilation
- crowded places where a large number of people gather
- close contact where you cannot keep 2 meters apart from others

In general, risk increases with the amount of time spent in these settings, the number of people present, and the likelihood of "forceful exhalation" such as sneezing, coughing or yelling.

The chart below will help you determine the risk level of specific activities. By analyzing information from a number of different evidence-based public health resources, ACE has selected the activities we feel are most relevant to the inflammatory arthritis patient community.

Low Risk	Medium Risk	High Risk
<ul style="list-style-type: none"> • take-out from a restaurant • grocery and retail shopping with proper precautions (mask, distancing) • playing physically distanced sports outside such as tennis, golf, running, hiking and biking • community parks and beaches if you are able to remain distanced from others • going for a walk • camping trip with your bubble 	<ul style="list-style-type: none"> • eating at an outdoor restaurant or patio • taxi/ride-sharing • public pools • movie theatre • medical appointments • hair salon • hotel • working in an office with co-workers (to learn about returning to work during COVID-19, click here) • young children playdates/ camp/ school 	<ul style="list-style-type: none"> • bars and nightclubs • crowded indoor restaurant • indoor party • gyms and athletic studios • conferences • hugging/kissing/ shaking hands • large religious or cultural gatherings • sexual activity with new people • crowded public transportation • air travel • high contact sports such as football, basketball or soccer

This information comes from the following sources:

- **Government of Canada - Going out? Do it safely!**
- **Ezekiel J. Emanuel – COVID 19 Activity Risk Index**
- **The New York Times – When 511 Epidemiologists Expect to Fly, Hug and Do 18 Other Everyday Activities Again**

3. Consider your individual circumstances

Patients must consider their unique circumstances and of their loved ones when making a decision. This does not only refer to your medical circumstances but also to your responsibilities, beliefs and values as well as the different resources and opportunities that each of us have access to. The Gerontological Society of America (GSA) has created a very helpful **decision aid** to help people tease out these factors and make informed choices about who to interact with and what activities to take part in during the pandemic.

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This decision aid encourages you to ask yourself a number of questions, including but not limited to the following:

- What is important to you in making this decision?
To what extent do each of the factors below matter to you?
 - Reducing your risk of becoming ill with COVID-19
 - Not making other people ill with COVID-19
 - Taking part in activities that give your life meaning
 - Spending time with people who are important to you
- Will you be able to do this activity at another time in the future?
- What is your risk level for COVID-19 and the risk level of those you interact with?
- How will participating in this activity impact those you care about?
- Can you modify the activity to make it safer? For example, could you walk, bike or use your own car to get to the activity rather than taking public transit or car-pooling with others?
- Who do you need to talk to before making this decision (i.e., healthcare professional, people in your household/ bubble)?
- Do you feel that you have enough information and support to make this decision?

Decision making and social justice

If anything, the pandemic has shown us how interconnected our communities are - the actions of one can have impacts on many. For example, a person's decision to wear a mask, make informed choices and isolate when they feel sick could help prevent a community outbreak. This is particularly important because, as stated by the [Canadian Human Rights Commission](#), COVID-19 has more severe impacts on the elderly, people with disabilities, families in poverty and Indigenous peoples. Making good decisions not only helps to protect yourself and your loved ones but also shows that you stand with other high-risk groups, many of whom are already marginalized populations. We have the opportunity to demonstrate compassion and solidarity with every safe action we take during the pandemic. To learn more about health inequities, check out our [Special Series](#) on the topic.

How to reduce risk: Traveling while immunocompromised


Traveling is considered a high-risk activity during COVID-19; however, a person living with arthritis may decide to travel after careful consideration or may need to travel due to essential reasons (e.g. work, family emergency, important life event). In these instances, there are certain steps that can be taken to reduce one's risk of contracting the virus. These tips come from immunocompromised ACE members who have recently travelled to a different province within Canada.

- **Consider all travel options and what their impacts are.**

There may be a possibility of taking a train, car, ferry or plane to get to your destination. Consider the cost, comfort and risk level of each option keeping in mind that a plane will be the most high-risk option as it is crowded and in an enclosed environment. It is also important to consider the way that each travel method will impact your disease. For example, driving may be safer than taking a plane, but could the long hours of driving cause a flare up of your disease? There is no “right” answer here, only different factors that are important to consider and may be worth discussing with your healthcare team.

- **Plan ahead; book in advance, if possible.** Most travel carriers are offering free cancellations so there is no risk associated with booking your trip ahead of time, even if your plans change. If you are taking a train or plane, booking in advance allows you to secure seats that are more “COVID-safe”. For example, seats at the front of an aircraft will generally have the best air flow as it circulates from the ceiling to the floor and from the front to the back of the cabin. On a train, you can choose a low traffic environment where people are less likely to walk past you. In addition, if you are traveling with others, ensure to book seats beside them as this reduces the number of people in close proximity to you who you do not know. **Recent research** has shown that it is people in close proximity to an infected person on a plane and train (e.g. seated across from, beside or in the next row) that are most at risk.





TIP: If possible, board last to avoid the crowded time period when people are finding seats, stowing luggage and walking around.

- **Pack a straw** so that you can drink fluids throughout your journey without having to take off your mask.
- **Have different personal protective equipment (PPE) options.** If you are able to get access to them, consider bringing a face shield and goggles in addition to your secure fitting facemask. At different points in your journey, a certain combination of PPE may be better suited or more comfortable for the setting. For example, while boarding an aircraft, you may want to wear a face shield in addition to your facemask to ensure your safety from those who are talking and shuffling around in close proximity.
- **Have a plan (or multiple plans!) for when you reach your destination.** If you are visiting people on the other side, you should talk about how you will interact when you see each other and be open about the possible risks associated with each option. Are you combining bubbles? Will you hug? Will you isolate for a period of time before interacting with each other? In addition, you should **make a plan for what will happen if you do contract the virus while you are there.** Will you be able to isolate safely from others? Will you have access to sufficient healthcare if complications arise? Are you able to remain there for a potentially extended period of time until you recover? If so, can you access your arthritis medications and healthcare team while you are there? Are there any restrictions on your travel insurance?

For a 'COVID-safer' travel option, consider camping! The Government of Canada considers this to be a low-risk activity. You can share tents and camping equipment with people in your bubble or you can camp physically distanced with people outside your bubble.

How to reduce risk: self-advocacy in everyday situations

People you interact with in your daily life such as family members, close friends or co-workers may act in ways that put you at higher risk for COVID-19 and make you feel unsafe. In these situations, it is important that you have the tools to advocate for yourself, particularly if you are living with inflammatory arthritis and are immunocompromised. Although speaking up can be challenging and uncomfortable, by doing so you are protecting your own health as well as the health of others. Here are some tips for having these conversations:

- Explaining your disease(s) may help others understand why you are at higher risk for COVID-19, and why their actions matter to you. Directing them to research-based on-line reading sources, like [jointhehealth.org](https://www.jointhehealth.org) and others, is a good place for them to start their learning process.
- Sometimes, comparing your inflammatory arthritis to other diseases better understood by the public is a good way to help others understand your disease. For example, people with type 1 diabetes require insulin on a daily basis to manage their blood sugar. Depending on the severity of their disease, people with arthritis require daily, weekly and monthly medications, often in combination. Medications often work by suppressing the immune system which puts you at higher risk for contracting COVID-19 and experiencing complications.
- You may need to communicate with someone you do not know as well, or even a stranger such as a cashier or service worker who is not practicing proper masking or sanitation. In these situations, here is a way to effectively and quickly practice self-advocacy:
“I have an autoimmune disease and I am at higher risk for COVID-19. It would help me feel safe if you could [describe the action you would like them to take such as proper masking, sanitation or social distancing]. If you can’t do this than I will have to [shop at a different grocery store, leave your business, etc.]”
- To develop more self-advocacy skills, consider taking one of our disease specific **JointHealth™ education courses**. They provide patients with the information, skills and confidence to be equal partners on their healthcare teams and effectively manage their world with arthritis.

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Going back to school? We want to hear from you!

We recognize that this is an incredibly challenging time for students as they navigate the new school year with COVID-19, while making decisions that impact your quality of life, health, education, and safety. We are looking to hear from:

- students with autoimmune arthritis (e.g. rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis) who are returning to school
- students returning to school who live with someone who has autoimmune arthritis
- parents/caregivers of a student with autoimmune arthritis who is returning to school
- parents/caregivers with autoimmune arthritis who live with a student returning to school

ACE wants to understand your experiences with back to school during a pandemic – including your concerns, insights, opinions, etc. We will share our findings with the patient community to help show families like yours that you are not alone.

If you are interested in filling out our short survey, please [click here](#).

Arthritis Consumer Experts (ACE)

Who we are

Arthritis Consumer Experts (ACE) operates as a non-profit and provides free research based education and information to Canadians with arthritis. We help (em)power people living with all forms of arthritis to take control of their disease and to take action in healthcare and research decision making. ACE activities are guided by its members and led by people with arthritis, scientific and medical experts on the ACE Advisory Board. To learn more about ACE, visit www.jointhehealth.org

Guiding Principles

Healthcare is a human right. Those in healthcare, especially those who stand to gain from the ill health of others, have a moral responsibility to examine what they do, its long-term consequences and to ensure that all may benefit. The support of this should be shared by government, citizens, and non-profit and for-profit organizations. This is not only equitable, but is the best means to balance the influence of any specific constituency and a practical necessity. Any amount remaining from our annual budget at year end remains with ACE and is used to support the following year's core programs to continue helping Canadians living with arthritis.

For its past 20 years, ACE has consistently honored a commitment to its members and subscribers, academic and healthcare professional

colleagues, collaborators, government and the public that its work is free from the influence of its funders.

To inform ACE employees and our stakeholders, members, subscribers that we will operate our organization with integrity and abide by the highest standards of lawful and ethical behaviour, ACE has adopted this strict set of guiding principles:

- ACE requests grants from private and public organizations to support its core program and plans and allocates those funds free from influence;
- ACE discloses all funding sources in all its activities;
- ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.
- ACE employees do not receive equity interest or personal "in-kind" support of any kind from any health-related organization;
- ACE identifies the source of all materials or documents used;
- ACE develops positions on health policy, products or services in collaboration with people living with arthritis, academic research community, health care providers and governments free from concern or constraint of its funders or other organizations; ACE employees do not engage in personal activities with its funders;
- Cheryl Koehn does not own stock or any financial interest in any of its private or public funders.

Thanks

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Disclosures

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ACE also received unsolicited donations from its community members (people with arthritis) across Canada.

ACE thanks funders for their support to help the nearly 6 million Canadians living with osteoarthritis, rheumatoid arthritis, psoriatic arthritis, ankylosing spondylitis and the many other forms of the disease.

Disclaimer

The material contained in this publication should not be relied on to suggest a course of treatment for a particular individual or as a substitute for consultation with qualified health professionals who are familiar with your individual medical needs. Please contact your physician for your own health care related questions.

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ACE does not promote any "brand", product or program on any of its materials or its website, or during any of its educational programs or activities.

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