

Challenges Faced by Students with Inflammatory Arthritis in an Online Learning Environment

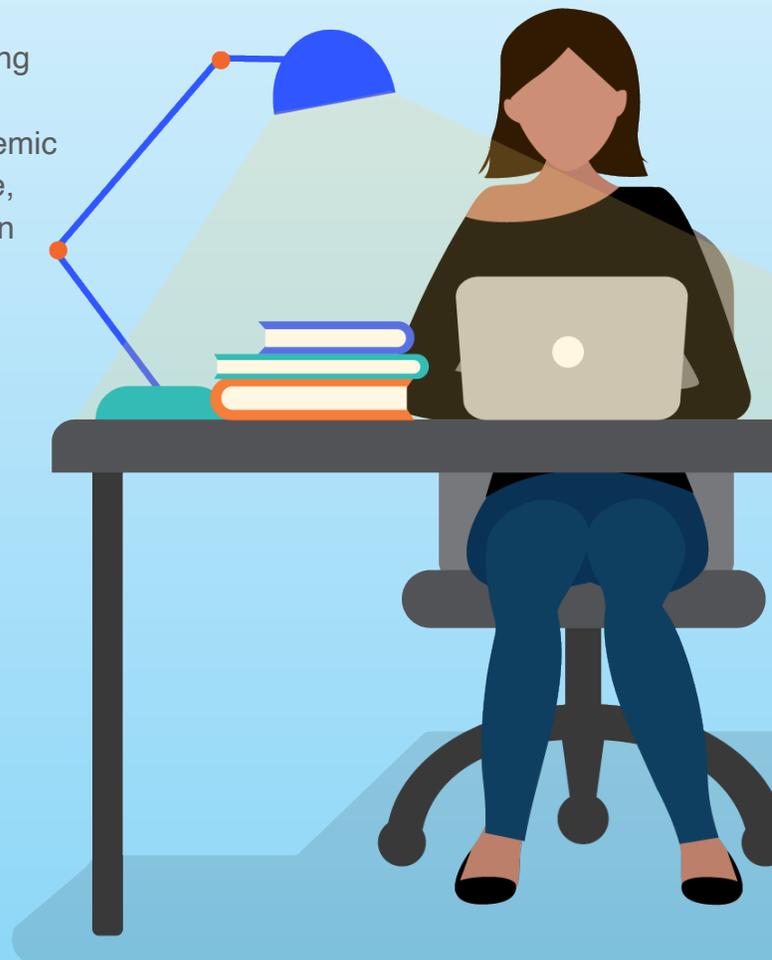


The ABC's of Learning in a Pandemic

As a result of the COVID-19 pandemic, in March 2020, post-secondary institutions across Canada began the transition from in-person classes to online education. Some of Canada's largest universities have announced that this model of education will continue into the fall semester, with the majority of classes being taught online and selected smaller classes delivered in-person. While studying or working from home does in fact offer benefits to people living with inflammatory arthritis (IA), there are times when high levels of disease activity make working in a classroom *or* home environment extremely difficult.

Overall, the expansion of online learning offers exciting opportunities for improving the accessibility of post-secondary education even after the COVID-19 pandemic is over. However, students living with chronic disease, such as IA, will experience unique challenges that run the risk of going unnoticed and require thoughtful solutions from post-secondary schools and their disability support centres.

This special edition of JointHealth[™] insight outlines challenges from the perspective of students living with IA related to self-advocacy and performance expectations in online learning environments. It is informed by current research as well as input from community members with IA who currently attend university and concludes with recommendations on how to address these issues.





What is inflammatory arthritis (IA)?

Inflammatory arthritis is a general term used to describe autoimmune forms of arthritis such as lupus, rheumatoid arthritis and ankylosing spondylitis. Contrary to the belief that arthritis only impacts older adults, these diseases can arise at any point in the lifespan, including during young adulthood, a time period that is often focussed on post-secondary educational advancement.

Inflammatory arthritis is characterised by the body's own immune system attacking healthy joints and other tissues, causing inflammation, fatigue, joint damage and even organ damage¹. Research suggests that systemic inflammation can also cause cognitive issues such as 'brain fog', an inability to think clearly and concentrate², as well as mental health conditions such as depression and anxiety³. During disease 'flare-ups', both physical and psychological symptoms are heightened and often result in an inability to work or perform usual daily tasks for potentially extended periods of time.

Self-advocacy challenges of online education for students living with IA

During flare-ups, it is particularly important that students feel comfortable advocating for their needs and taking necessary rest periods or 'sick days' in order to focus on pain management and recovery. However, when classes are moved online, students living with IA find it more challenging to seek accommodations and advocate for their needs, an issue which is described in detail below.

Most, if not all, post-secondary institutions have an accessibility centre where students with disabilities can receive academic support and accommodations such as extra time and use of assistive technologies (e.g. computers) for final exams. However, students generally have to practice some level of self-advocacy and communicate directly with their instructors when it comes to accommodations for regular course work, assignment extensions and classroom absences⁴. Interview-based research has shown that post-secondary students with disabilities, particularly 'invisible' disabilities like IA, already face challenges advocating for themselves in standard, in-

person classroom environments. For example, in a 2018 study involving 105 students with disabilities from England, Canada, Australia and the US, nearly 20% of participants specifically mentioned that they had concerns about instructors thinking they were 'lazy' or faking their condition⁵. One Canadian participant with an invisible condition stated, "I have never had a professor understand that when I miss classes it is because I am sick, and not because I'm just using my conditions as an excuse for laziness" (page 239). Students with invisible disabilities such as IA often find that their needs are not fully understood unless their instructor has some personal experience with a similar condition, which impacts their willingness to seek accommodations or disclose their disability⁶. For example, the invisible nature of IA has been identified as a key challenge faced by young adults living with the disease across their school, work and personal lives, as they often feel that others do not take their limitations or complex symptoms seriously⁷.

Why are these challenges made worse in an online learning environment?

Students are less likely to be comfortable disclosing their condition(s) and asking for accommodations when they do not have a face-to-face relationship with their instructor. Generally speaking, fears about being viewed as 'lazy' or 'faking-it' are heightened for students with physical limitations due to perceptions they have a greater ability to attend online classes and perform well in them compared to in-person ones. Instructors are generally not aware that disease activity can, at times, make working or learning in any environment extremely difficult and that IA consists of more than just physical limitations. ACE members who are students have told us how their non-physical symptoms experienced during a flare, such as severe fatigue and cognitive impairments, are rarely understood by instructors whom often seem shocked when accommodations for these issues are requested by the student.

ACE's Program

Coordinator, Maya Joshi, described her personal experience during the last four years attending three different post-secondary institutions in Canada: "I have had the opportunity to connect with many students who live with chronic disease(s) like myself and/or other health conditions that impact their daily lives.

Over the years, it's become clear to me that schools work hard to support their students with disabilities but that there are some critical areas where this support could be strengthened – including those outlined in this JointHealth™ insight. It is important that these issues be brought to the attention of post-secondary institutions and their disability support centres before the fall semester and ACE intends to make that happen through our ongoing advocacy work."



Not only do students with chronic diseases like IA experience a wide variety of challenges which will persist in online learning environments, but they are also experiencing entirely *new* challenges in online classes, which their instructors are often not aware of. For example, some students face worsened pain and inflammation in their hands because of additional computer work in online classes that often replaces in-person discussion-based activities. In addition, an undergraduate student with ankylosing spondylitis told ACE:

“Working from home burdens us with new challenges that are different but equally demanding compared to the barriers of a physical campus. For example, I used to rely on the 10-minute break between classes, and the transportation time between meetings, to stretch my joints and get my blood flowing again. That was in addition to frequent physiotherapy, IMS needling, cortisone treatments, etc. which I currently can’t access due to the COVID-19 pandemic. To make up for this, I sometimes need to ice my sore muscles/rest my joints in bed/submerge myself in warm water/do strange stretches during meetings and lectures. It would be much more convenient if I could keep my video off while still engaging as an active listener and verbal participant, but expectations are often to ‘make sure your video is on to demonstrate that you are fully present’. I wish my supervisors and professors understood that having my video-chat off is not inherently proof of a decreased level of engagement.”

In summary, students living with chronic disease like IA are facing both new and existing disease-challenges in online classes while simultaneously experiencing more difficulty advocating for their needs. Self-advocacy barriers are brought on by the combination of performance expectations, limited awareness about inflammatory arthritis, and an absence of in-person relationships with their instructors. These issues are important because an inability to undertake self-advocacy ultimately impacts one’s ability to manage their disease. In the case of inflammatory arthritis this can result in increased inflammation, pain, fatigue and potentially permanent joint damage.

Potential solutions

Solutions to disease-challenges in online learning must include both action and perspective shifts by instructors and institutions, as well as students living with chronic diseases. Suggested supports that can be implemented at potentially low cost by post-secondary institutions are highlighted below.

1) Advocacy support from post-secondary institutions

As noted earlier, an institution's accessibility centre can provide critical support for students with disabilities but there is often a gap when it comes to supporting students in their regular communication with instructors throughout the term. This communication is often more difficult in online classes making it that much more important to provide students with the tools to communicate effectively and confidently with their instructors about their limitations when needed. Although some self-advocacy programs do exist, typically developed by patient organizations, not all students with disabilities have access to them or are even aware that these programs are available. Therefore, it would be beneficial for accessibility centres to offer their own self-advocacy workshops or webinars on a yearly basis to ensure that all of their students have the opportunity to develop self-advocacy skills which can be used in both in-person and online learning environments. Research has emphasized the important role of self-advocacy training in the success of post-secondary students with disabilities⁸, with communication being a key component of self-advocacy⁹.

One particularly helpful, and practical resource that institutions may wish to consider providing is templates of emails which students can use to communicate with instructors when advocating for accommodations. For example, if a student is unable to attend class or needs an extension on an assignment as a result of their disease, they can email their instructor using these templates, simply filling in information specific to each circumstance and/or amending them with details relevant to their situation. These templates should be developed in partnership with the student and their accessibility advisor to ensure that they align with:

- 1) the institution's policies regarding attendance,
- 2) the student's 'registered' accommodations, and
- 3) the student's personal level of comfort in disclosing their disease.





For example, some students may be comfortable disclosing more details about their disease while others may wish to provide limited information, and this preference should be reflected in the email templates. Providing these templates and reassuring students that they are not required to disclose extreme amounts of personal information can prevent the following situations identified by ACE student-members:

“I can’t tell you how many times I have gone to class or completed an assignment in extreme pain, knowing that it will take a significant toll on me, just because I don’t know what to say to my professor and am worried about what they’ll think of me as a student. Even though I am registered with the accessibility centre and I am allowed to ask for extensions, the process of actually communicating with my prof about my disease can make me so anxious that sometimes I just choose not to altogether. This happened more often when classes moved online at the end of last semester because I didn’t really know how to explain my need for these accommodations without writing them a whole email essay.”

— Undergraduate student with rheumatoid arthritis

“I often feel pressured to tell my profs way more than necessary in order to feel like I have a good reason to ask for extensions or justify absences, which results in an absurd amount of time spent mulling over precise email wording and context framing.”

— Undergraduate student with ankylosing spondylitis

2) Increasing knowledge and awareness within institutions

While it is important to improve self-advocacy skills and resources, this approach means that students with disabilities are primarily responsible for improving the accessibility of their classrooms rather than it being a collaborative approach including their instructors and other members of the institution. Students with invisible disabilities like IA have recommended that university staff and faculty receive education about different types of disabilities to facilitate a better understanding for them¹⁰. This will

lower the chance of students receiving a negative response when they advocate for their needs. Additionally, knowing that these awareness programs are in place will allow students to feel more comfortable disclosing their illness and asking for accommodations, even when they do not have an in-person relationship with their instructors. Ideally, this education should be led by patients in the university community to ensure that it aligns with their lived experiences.

Although online classes may be more physically accessible, higher expectations relating to attendance and performance – whether intended or not – should not be placed on those living with complex physical disabilities like IA. Instructors should recognize that some of their students will continue to face challenges in online classes and require accommodations for conditions which they may not see, or fully understand in addition to those challenges brought on by the current pandemic. Accommodations include adjusting expectations around synchronous learning and online meetings, such as those that include ‘video on’ policies and mandatory attendance. Instructors should approach these instances with compassion for their students and awareness for the complexity of their chronic conditions; acknowledging that students’ needs will fluctuate in correlation with both physical and mental symptoms.

Go Deeper

An additional consideration for students with IA or other chronic disease

Students must also be encouraged to practice self-compassion and avoid setting higher expectations for themselves due to a shift in the learning environment. Some people who have transitioned to working or learning from home as a result of the pandemic (both with and without chronic disease) have reported higher levels of fatigue and ‘burn-out’ as they place greater expectations on themselves and often experience blurred boundaries between work and/or academics and personal life.¹¹

It is particularly important that students with chronic diseases set aside time for themselves and create healthy boundaries between daily responsibilities. For those with inflammatory arthritis, daily ‘disease responsibilities’ often include physical activity and taking periods of rest throughout the day. Students must ensure that they continue caring for themselves and being mindful of their limitations. Above all, students must feel comfortable speaking up for their needs in an online learning environment – something which will be much easier when they have more meaningful support from their institutions and instructors.

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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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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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