

Patient Perspective: Kelsey Chomistek

At age 15, I started feeling sore and began limping each morning. As a competitive dancer who trained seven days a week, I initially dismissed the pain and fatigue. I thought I was twisting my ankles, and that my busy schedule was making me tired. My dance instructors said my technique was declining and that I was growing disinterested — despite arriving early before each class to practice. They also put me on a high-protein diet to gain weight.

At Alberta Children's Hospital, I learned why I was struggling: I was diagnosed with rheumatoid factor positive polyarticular juvenile idiopathic arthritis.

It was incredibly challenging to be given this diagnosis as a teenager. I spent the first day of every school year getting an infusion in the medical day unit. I was often too exhausted to attend social events, I was always late for school, and the side effects of my medications made me sick on the weekends. I continued to compete, managing my arthritis symptoms by taping my ankles, using ice and heat packs, taking breaks in class, reducing my dance schedule, and starting medications (prednisone, naproxen, methotrexate, and etanercept).

One year after my diagnosis, my dance studio notified me by email that I could no longer be a member of the studio if I was unable to meet their requirements. As a dancer since age four, I was devastated. I felt like I had lost a piece of my identity and felt suddenly isolated from my peers. I was able to graduate high school with distinction despite a significant number of absences due to medical appointments, and I started my undergraduate degree in health sciences. My degree became my next challenge, as I tried to navigate a rigorous program and an uncontrolled disease. During my second year, I had a synovectomy of my right wrist due to persistent inflammation and pain. I vividly remember the professor who stated that I would have to take a 0 on my midterm because my surgery was scheduled for the same day as my exam. I recall crying in the library as I tried to write notes to study for my final exams two weeks post-operatively. I did poorly on my exams that year, and my grades continued to decline, as I struggled to complete the following semester with a wrist that was taking longer than anticipated to heal. I was told I could either trans-



fer out of my program or risk being kicked out of university due to being placed on academic probation.

This was the second experience where I felt like my arthritis had taken something from me — my lifelong dream of becoming a physician. I reluctantly transferred programs, and during the summer of my third year, I had a synovectomy of my left ankle less than 24 hours after writing my Medical College Admission Test (MCAT).

Following my undergraduate degree, I started a Master of Science in Medical Sciences, working with Dr. Heinrike Schmeling and Dr. Cheryl Barnabe, supervisory committee, and team at the Alberta Children's Hospital to develop a self-management program for ado-

lescents with juvenile arthritis. This project was important to me because I wanted to make the transition to living with a chronic illness easier for patients and families. I wanted patients to have the skills required to manage their disease and to learn to advocate for themselves to minimize the challenges that I had faced. As I continued my degree, I slowly lost my ability to walk, as I wore down the cartilage in my left ankle and eventually needed a knee scooter to mobilize due to the pain. Losing my ability to walk remains one of the hardest experiences that I have had to face since my diagnosis. As a previously healthy and active individual, I simply never imagined that I would need to decide between an ankle replacement or ankle fusion and have to live with the consequences of my decision. I opted for a total left ankle replacement, and at age 23, I learned how to walk again for the second time. I used the time recovering from my surgery to submit my medical school applications. In 2020, I received a different kind of email. I was accepted into medical school at the University of Calgary.

Now at age 27, I have spent 13 years living with inflamed joints, pain, stiffness, limited range of motion, and fatigue. My subtype has been treatment-resistant and has resulted in erosive changes and irreversible joint damage. My disease has remained poorly controlled during my medical training, and it continues to be challenging as I pursue my career and learn how to navigate balancing my health, countless appointments, career, and personal responsibilities. The hardest part of living with a chronic illness is that it is an invisible disease. It is difficult for people to truly

Update from the Canadian Academy of Sport and Exercise Medicine

Choosing Wisely: Pediatric Sport and Exercise Medicine Recommendations

By Kristin Houghton, MD, MSc, FRCPC, Dip Sports Med

Choosing Wisely Canada (CWC) is the national voice for reducing unnecessary tests and treatments in Canada. A small working group (Laura Purcell, Erika Persson, Kristin Houghton) created by the Canadian Academy of Sport and Exercise Medicine (CASEM) developed a list of pediatric-specific sport and exercise medicine recommendations based on existing research, experience and common practice patterns. These recommendations identify tests and treatments commonly used in pediatric musculoskeletal assessments which are not supported by evidence and could expose patients to harm. Pediatric rheumatologists frequently see children with non-inflammatory musculoskeletal pain and are encouraged to adopt these CWC recommendations as part of routine practice. The list includes imaging recommendations for Osgood Schlatter's disease, shoulder and knee injuries, back pain, scoliosis, spondylolysis, distal radial buckle fractures, mi-

nor head injury/concussion, and management of chronic pain syndromes. This list launched on April 12, 2022 on the Choosing Wisely and CASEM websites.^{1,2} (choosingwiselycanada.org/recommendation/sport-and-exercise-medicine-for-steve/#pediatric-sport-and-exercise-medicine)

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References:

1. Choosing Wisely Canada. Available at choosingwiselycanada.org/about/. Accessed June 2, 2022.
2. Canadian Academy of Sport and Exercise Medicine. Available at casem-acmse.org/. Accessed June 2, 2022.

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understand the symptoms I am experiencing when I look like an otherwise healthy young adult. It is also difficult to reconcile the feeling that who I am as an individual isn't being accurately portrayed due to my physical limitations and fatigue. I became involved in the arthritis community because I wanted to raise awareness, to show others what it really means to live with a chronic illness, and to share my experience with families to make this diagnosis easier to manage. I am co-founder of the Teen Arthritis & Auto-inflammatory Group (TAG), and in partnership with Cassie and Friends Society, we have expanded TAG across Canada to provide peer support for adolescents diagnosed with pediatric rheumatic diseases.

I am currently in my last year of medical school and one of my teenaged patients had also lost their ability to walk.

On the last day of my rotation, they were able to bend their knees without pain for the first time. For the first time since my diagnosis, I cried because arthritis had given me back something even more meaningful in life — the opportunity to truly understand what my patients are going through and help them realize that they are not alone.

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