

# Patient Perspective: Carrie Barnes

At the age of 32, I became unable to care for myself or my family. Every aspect of my life was affected by swollen, painful joints. Simple tasks like preparing food and getting dressed were no longer possible without help from others, even my ability to chew was unpredictable. I felt lost and scared, having trouble recognizing the person staring back at me in the mirror.

At the time my symptoms started, we had recently moved across the province, leaving me without a family doctor. Relying exclusively on walk-in clinics made it nearly impossible to have any continuity or consistency to my care. My body continued to change at an alarming rate, leaving me more and more incapable by the day, and after struggling to keep up with the demands at work, I was connected to a local interdisciplinary rheumatic disease clinic. From that point on, things started to change for me.

It is quite an experience to be diagnosed with a chronic illness. I'll never forget the day I was given mine. In some ways it's a relief to give symptoms a name instead of just "pain" or "illness," but all I heard was, "chronic, injections, medication, appointments . . ." I went from, "Finally! A diagnosis!" to "Please no. I can't do this." I was overwhelmed and felt alone and truly incapable of taking a step in the direction I needed to (pun intended).

At the clinic, I was assessed, triaged, and seen in a timely manner by several of the healthcare team members. I was never asked to repeat the same test, scan, examination, or assessment, never asked the same set of questions, and was always included in the dialogue about my care. A welcome change after the revolving door I had experienced previously and the broken record I felt I had become.

I remember sitting in a room surrounded by a variety of healthcare professionals; social worker, occupational therapist, pharmacist, physiotherapist, and rheumatologist, all discussing my care, all reading off one chart, my chart. I could tell they respected each other's roles and input by the way they communicated and interacted. Witnessing a group of providers come together, bring their professional best, share their expertise, and



then create a plan as a unified whole, gave me the confidence I desperately needed to do MY part...the follow through.

Soon after diagnosis, I attended an education session at the clinic, delivered by the various healthcare disciplines. I was provided with knowledge about my illness, my medications and how to begin to understand what was going on in my body. I was taught to recognize subtle changes and symptoms before they became bigger issues; skills I use to this very day, skills that have kept me out of the emergency room for nearly a decade and a half. And lastly, I was shown how to

contact and access the various team members when I needed assistance.

My care didn't end at diagnosis. There have been ups and downs along the way, but I have been able to access the specific care I've needed with the appropriate team member each time. Everything from tweaking my orthotics, ordering specific medications for travel, addressing a joint before it flared, injections and everything in between, my team is available and ready to assist as needed.

I have remained employed, been on many grand adventures and engage in life to the fullest of my abilities. I would not be where I am today if it weren't for the interdisciplinary care I received and continue to have access to.

*Carrie Barnes, Patient Advocate Ontario*



The author on the Lake Superior Coastal Trail.