



Canadian Women's Heart Health Alliance Advocacy Working Group | Member Profile



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Woman with Lived Experience

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Alliance member since 2022

Biography

I was misdiagnosed for the better part of a decade. Symptoms started at age 28/29. I finally received an official diagnosis at age 38.

My symptoms started initially with exercise intolerance, shortness of breath, chest pressure that would come and go, headaches and nausea. I went to get checked out several times during those years and was consistently reassured it was nothing but stress. At the time, I believed that answer.

One day however, I while was cleaning cabinets, I experienced every symptom of a woman having a heart attack. It was unmistakable. A contraction like squeezing in the left side of my chest, pain running into my left arm and down to my wrist, pain in my jaw, nausea, a feeling of doom and sweating. My mom drove me to the ER. I had some tests suggesting my heart wasn't getting enough oxygen and then others suggesting everything was fine. So I was sent home with muscle relaxers and some tips on stress management. Ever since that day in August 2014, I have had chest pain every single day.

Over the following years I would continue to have events like the one I just mentioned, along with the daily chest pain. I continued to search for answers. My symptoms were consistency attributed to female issues like pregnancy, stress and hormones. I had had a complicated pregnancy in 2012/2013 and so everything initially was blamed on the stress/trauma from that pregnancy.

I would spend the next few years fighting for my life while circling in a holding pattern of Gastroenterology-Cardiology-Rheumatology-Neurology-Immunology-hematology - psychiatry and pain clinics, only to end up repeating the cycle over and over again.



My breakthrough came when googling my symptoms in different orders, finally returned a match. It was a link from a Medscape comment. I followed the link and reached out to its' author. She immediately sent me the link for her microvascular disease/non-obstructive heart disease support group and that's when I knew what was happening to me. I would spend the following years trying to convince my physicians it was, definitely 100% my heart. I thought I would bring this information back and I'd be met with compassion, treatment and my life back. That was not the case.

I had been seeing a local cardiologist who agreed something was wrong but did not believe it was my heart, especially after all my tests came back "normal." There were, however, so many things missed during that time. I remember spending a few days in the CCU and during that time completed a treadmill stress test. I had left sided chest pain during the test and that evening I had so much chest pain, I was ringing for the nurse every hour but the tests were normal, so I was inevitably sent home on Christmas Eve with a referral to a pain clinic and a recommendation to take high dose Tylenol Arthritis.

During this time, my marriage was struggling, I lost my career, I lost friendships and I went from being a strong, confident, and independent woman to a tired, scared, anxious shell of a human who couldn't even push her children in their stroller or read to them due to shortness of breath. Yet somehow, it was all being caused by anxiety.

I continued to struggle. Seeing cardiologists and being told, "it's 100% not your heart." Through a NOCAD support group, I found the name of a doctor who would change the trajectory of my journey.

Dr. Tara Sedlak responded immediately to my emailed plea for help. She acknowledged my concerns and agreed with my "self-diagnosis" of microvascular disease. She recommended I come see her as soon as possible. I packed up my little family and we drove 17 hours to consult with Dr. Sedlak. She was everything I needed her to be. She listened to my story in full, she acknowledged and addressed my fears and concerns. She was honest with me about my hopes for longevity. I felt heard, I felt validated, I felt relief.

Unfortunately, over the next few years I would not respond well to medications due to either side effects or they simply would garner no change in my symptoms. Dr. Sedlak would try all possible meds and even order one from Italy that was not yet available in Canada. I was so grateful for her! I still am! During this time, living with a "suspected" diagnosis would become a very difficult thing for me here in Edmonton. ER doctors and other specialists did not seem keen on accepting a diagnosis that wasn't backed up by a positive test. To them, my cardiac tests were all "normal" and therefore I did not have heart disease. My local cardiologist still tried to help me; however, I'd go six to eight months after a med change (that wasn't helping) before seeing him again. He wanted to help but the information on how to help just isn't there.

My diagnosis finally came after a new type of angiogram became available at the Mazankowski Heart Institute. Dr. Sedlak let me know they were planning on offering this new angiogram, so my GP made the referral immediately and I was contacted days later by Dr. Alexandra Bastiany. After years of being told "it's not your heart," it took new technology and a new way of



visualizing the heart under stress to finally secure a diagnosis.

One would think that after all this, I would have a happy ending. The truth is, I am still struggling. I searched Canada for a cardiologist to operate on my myocardial bridge. I found a surgeon in Toronto who said he would do it after reviewing all my test results. Covid put my surgery on hold in Toronto indefinitely. I've enlisted my local cardiologist to see if anyone on his team would be interested in doing this surgery here in Edmonton. He said he would bring it to his team. That was 10 months ago. Every time I speak with him, he says he doesn't know and that he will check. So again, in this holding pattern of uncertainty.

I still am not on medications that help. I live every single day with debilitating angina. I've learned to pace myself, taking large rest breaks between things I need to do and avoiding things I know will trigger severe pain.

I do have hope. I will continue to pull myself through pain, uncertainty, and setbacks. I will continue to advocate for myself and other women while continuing to stay up to date on the latest emerging research.