



Ebony's Story

Diagnosis & Unsurprised Response to Treatment

When I was diagnosed with Endometriosis, I felt relief and had an emotional heart attack. Once my gynecologist explained that I would have a laparoscopy and then an Mirena IUD to reduce heavy bleeding, cramping and likelihood it would come back. I also felt sad that I hadn't already had children and wondered if it explained why I had not got pregnant from using the rhythm method for 5 years. Deep down, I wished that it had happen as I love children. I had testing and it showed that I was dual ovulating (releasing 2 eggs a month) and I had a very high egg count. I was encouraged to have children as soon as possible because I would have challenges later. I was no longer in a relationship and struggling with other issues. I was not in the right position to be making big life changing decisions. It caused me a lot of depression and it would have ended in crying spells/anxiety. Following thoughts of inadequacy, loneliness and helplessness. I never knew what Endometriosis was and now I was faced with potential infertility. It made my self-esteem plummet as I felt I was unlovable if I was not fertile. A potential partner might say they don't want kids, then change their mind. Was I ready for that journey of heartbreak? I come from a family of 8 and my mother from a family of 9. Then came feelings of self-consciousness, can these other women tell that I am infertile? Seeing women bonding with their babies and children.

Rapid Health Decline, Shock of an Additional Diagnosis and Rollercoaster of Emotions

My treatment journey took a massive twist. I struggled with severe PMS Mirena IUD and had to journal my symptoms for regular review. I noticed patterns in my struggles and each month it got worse. I developed debilitating anxiety attacks as my progesterone levels peaked, hypersomnia, fatigue, ultra-rapid mood swings and binge eating disorder. At 6 month point, I described these patterns in the second half of my cycle and was alerted that what I was describing was Premenstrual Dysphoric Disorder caused by Progesterone Intolerance. Due to the contradicting treatments, my gynecologist tried to desensitize me to progesterone by riding it out as it was the lowest dose release treatment available to keep the Endometriosis away. My condition continued to deteriorate and I ended up in emergency with ultra-rapid mood cycling, suicidal ideation with a planned attempt, non-stop binge eating with no satiation, non-stop anxiety attacks and severe pelvic inflammation. I also suffered from low estrogen symptoms or menopausal symptoms with memory loss, brain fog, muscle pain and joint pains. The hospital sedated me and administered pain relief. My gynecologist removed my IUD the following day and I had no hormonal treatments for 3 months.

Treatment Attempt 2 & 3 – Life’s Cha-cha

I started another hormonal ratio treatment high in estrogen and had ovulatory pain with heavy bleeding. My treatment was upped again and I had mental relief from the depression and anxiety induced from progesterone. My Endometriosis pain and heavy bleeding returned. It was time for another laparoscopy. Treatments for Endometriosis requires a suppression of estrogen and treatment for Premenstrual Dysphoric Disorder require an increase in estrogen with a suppression in progesterone. I was confronted with 2 undesirable effects. If I treat the Endometriosis, I would pain free, but crazy. If I treated the Premenstrual Dysphoric Disorder I would be mentally healthy, happy and in a great deal of pain with heavy bleeding. Pain or insanity? The treatment I am currently keeps me with a reduced response for both, but neither complete relief from one or the other. I thought the Endometriosis would be the cause of my pain, not just the fuel of hormones or absence of them. I'm still fighting and I am proactive in finding the answers. I hope my story helps others in a similar situation to feel less alone. I have forgiven my medical team for many decisions, but am grateful for their ongoing commitment to my care. There was no way of knowing and it was unfortunate due to the rareness of progesterone intolerance and lack of deep understanding about Premenstrual Dysphoric Disorder.

Career Implications – Reality of Reduced Work Capacity to Part-time

Endometriosis had robbed me of my career and created many forks in the road. Completing my final 10 week practicum twice and ending up in hospital part way through due to stress exacerbating endometriosis pain. Not being able to walk properly and hurdle over in pain and tears due to frustration. My dream job was still merely a dream. Stuck at the finish line for 3 years because of Endometriosis. My job choice was a high stress, high workload and psychically demanding job. If I had known I had Endometriosis, I would have chosen a more stress reduced job. I agreed to try again. Depressed and asking my university for practicum adjustments to cater to my physical and mental challenges with letters from my doctor, gynecologist and psychiatrist for part-time extended practicum to reduce stress/workload to prevent a flare up. It was rejected as the course requires a full-time practicum completion to graduate, despite mentioning that I would only be working part-time.

Getting on with it. Acceptance of Endometriosis, Connecting with other Endo Sisters, working on improving overall Health, Wellness, Stress Management and Fighting for my Dreams with the Help of a Strong Advocate

I am up skilling, working on a mindfulness course, stress reduction courses and working on nutrition. I have had massive relief by going gluten and dairy free. I've agreed to keep fighting to do my dream job with hope once completing the final practicum, I will teach part-time. I won't let Endometriosis stop me from doing what I love. It's hard trying to get empathy and accommodations for invisible illnesses. Cries falling on deaf ears and not feeling heard. Personal embarrassment and insensitivity due to it being a female reproductive condition. It was so hard for me to disclose it. I will keep taking my good friend to be my mentor to advocate for me in meetings with the university. This helped me to hold myself together when I wanted to crumble and cry. It was wrong. The adjustment was fair and equitable. The message I am getting is that if you have a physically and mentally distressing disability like Endometriosis means that you can't do the course at all. Full time or nothing to gain accreditation. Why do I have to keep ending up in hospital due to lack of flexible adjustment? I speak up for all those who are struggling at school, university and the workplace. This is discrimination and dismisses the "invisible" condition. Don't be silenced by others. Don't let others define your capabilities. Be assertive and put them in your shoes. "If I was your child, what would you do?" Empathy needs to be taught. Take someone strong, supportive and knows your story inside out with meetings. It is not a sign of weakness to have an advocate, it is a sign of strength to have someone support you. Connecting with my Endo

sisters along my journey has really helped me. We all know the struggle and support each other with knowledge, care and sensitivity. It's good to not feel so alone in social isolating conditions at times of ill health.