Seizing Life, episode 86
A Young Woman’s Epilepsy Journey of Acceptance, Empowerment and Advocacy
Guest: Kiara Mowat
(Transcript)

Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes. And this is Seizing Life. A biweekly podcast produced by Cure Epilepsy.

Kelly Cervantes: 00:17 Today on Seizing Life. I'm happy to welcome Kiara Mowat to the podcast. Kiara has lived with epilepsy since the ninth grade. She is now a first-year student at McMaster university in Hamilton, Ontario. In honor of Epilepsy Awareness Month in Canada, Kiara is here to tell us about her journey with epilepsy. The physical and emotional impact that it had on her during high school. And the challenges that epilepsy is presenting during her first year at university. Kiara, thank you so much for joining us today to start. To start I want to talk about when you experienced the circumstances around your first seizure and when you were initiated into this crappy epilepsy club.

Kiara Mowat: 01:02 I had my first seizure when I was coming back from musical rehearsal. I was in grade nine and I was in Beauty and the Beast. And I remember coming back home and I have a brother and a sister. And that night, for some reason, the three of us, we were like, "Oh, let's have a sleepover in our mom's room." And so the three of us, we slept with my mom that night and really early that morning, I don't know what time. It must have been like two, three in the morning. I had my first grand mal seizure and thank God that my siblings and my mom were with me because I honestly don't know what would've happened if I were all alone. And I remember just going in and out of consciousness and the police were around me and there were firefighters in the house and I was totally unaware of what was happening. And I thought that something had happened to my mom or my brother and my sister. And I didn't even know that something had happened to me. It was just like my world had completely shifted.

Kelly Cervantes: 02:28 They take you to the hospital, and what did the doctors tell you at the hospital?

Kiara Mowat: 02:34 So initially they thought that I had overdosed because you have a 14 year old coming back from a high school play. And they kept asking me, like, "What did you take? And what drugs did you do? And were you actually at musical rehearsal?" I remember being asked that in the ambulance, like, "Where were you?" And I kept telling them, "I didn't do anything. I was really at musical rehearsal." And it felt like no one truly believed me in that moment. And in the hospital, I was just completely... My body was just so exhausted from the seizure that I was just

		in the bed and they were just doing blood tests and I did a CT scan, and my mom was just terrified. And it was just a large moment of not knowing.
Kelly Cervantes:	03:34	Yeah. The fear and the unknown.
Kiara Mowat:	03:38	Yeah.
Kelly Cervantes:	03:39	I think is one of the worst aspects of those very first, early moments or days on a person's epilepsy journey. And so what was it like? When did you get the epilepsy diagnosis?
Kiara Mowat:	03:55	So I did my first EEG after I left the hospital. And then my first seizure happened in April of 2018. And then I don't remember when I did the EEG, but then I received the results in June of 2018. And I didn't have to have a second seizure for them to say that I had epilepsy. I just did the EEG. And I remember going to the doctor's office of my family doctor. And I just remember sitting on the little bed and stuff. And he said to me, "You have juvenile myoclonic epilepsy." And I just broke down in tears. I didn't know what that meant for me. I didn't know what that meant for my future. And it's a moment of uncertainty, because you don't know what's going to happen to you.
Kelly Cervantes:	04:53	What did the doctor tell you about juvenile myoclonic epilepsy?
Kiara Mowat:	04:57	Nothing. He told me nothing. He's just like, "I'll direct you to a neurologist and you can move forward from there." But at that moment I wasn't educated.
Kelly Cervantes:	05:11	So this was your pediatrician who was giving you this diagnosis?
Kiara Mowat:	05:15	Yeah, this was my family doctor. Yeah.
Kelly Cervantes:	05:18	So you get a referral to go and see a neurologist. Did the neurologist give you more information?
Kiara Mowat:	05:24	No. So there was very much a lack of education. And I think now, as I'm getting older, as I entered university, as I'm becoming a woman out into the world, I've decided to educate myself. And that's how I found CURE Epilepsy and Epilepsy Canada, and just all these amazing organizations and that have educated me. And I've kind of said to myself, "Wow, I have these doctors in my life, but why haven't they educated me? Why haven't they educated my parents? Why haven't they educated my family members?" And it's just the people that are supposed to help me, that supposed to support me, they

haven't in the way that I've wanted to and the way that I've needed to, and in the way that they should. It was just, "Okay, this is your medicine. And this is what we're going to do. This is your treatment."

Kiara Mowat: 06:30 And I didn't know that there was brain surgery as a treatment. I didn't that there was CBD treatment. I didn't know that people were doing acupuncture and all these different forms of... Different ways to just treat seizures and epilepsy, especially for people who have drug resistant seizures, which are mine.

Kelly Cervantes: 06:55 First of all, I want to say, I'm so sorry that has been your experience with your epilepsy diagnosis and the lack of information that was provided to you and resources, and that you had to go out and find it on your own. Unfortunately, I think that happens far more than it should. But I'm curious, what was the treatment plan that was prescribed to you and how has that changed over the years?

Kiara Mowat: 07:23 It hasn't. I've been on the same two medications since my diagnosis, since 2018. And it's now 2022, which is insane. Honestly.

Kelly Cervantes: 07:38 Have you requested to try other medications since those two are clearly not working?

Kiara Mowat: 07:44 Yeah. But it's just, "Oh, we'll just shift the dosage. We just need to find the right dosage for you. It's just trial and error." And it's been trial and error for almost four years now. It gets to a point where you feel like the medical system has failed you and everyone involved. And I feel like people with epilepsy and caregivers of those with, too, epilepsy. Yes, you should be educating yourself. But when you're first diagnosed, you should be given support. You should be given resources. And I feel as though that wasn't given to me, that wasn't given to my family.

Kelly Cervantes: 08:28 Now, I'm curious because I'm not very familiar with the medical system in Canada. Now, are you able to go and request a second opinion from another doctor?

Kiara Mowat: 08:42 Yeah. And so that's what's been happening now for me in the past two months, because I've had the same neurologist since I was 15 and I'm turning 19 soon. And so, taking that... I feel like a lot of people who have such a huge diagnosis like epilepsy. If you've had a neurologist for such a long time, especially since the beginning of your diagnosis, it could be really scary to try to go find another neurologist who's been with you since the very beginning.

Kelly Cervantes: 09:18 I think, it's a really honest observation. What I will say is that... And I also... Because I went through this with my daughter where at times I felt guilty going out and seeking another opinion. Like I wasn't trusting this other doctor that had, but what I learned is that excellent doctors respect and often, especially with a complicated diagnosis like epilepsy, an excellent doctor appreciates you going out and getting a second opinion and adding to the ideas of the treatment care plan. Because the more minds involved in these sort of situations, the better. And perhaps you find a doctor that is more experienced or is more knowledgeable about your particular kind of epilepsy or the different treatments that are out there and that are available.

Brandon: 10:16 Hi, this is Brandon from CURE Epilepsy. Did you know that 30% of those diagnosed with epilepsy do not respond to current medications? That is why for over 20 years CURE Epilepsy has been dedicated to funding patient focused research to find a cure for epilepsy. Learn more about our mission and our research by visiting cureepilepsy.org. Now back to Seizing Life.

Kelly Cervantes: 10:40 While you've been speaking, I can't help but in the back of my head be thinking about the fact that all of this is happening to you when you're in ninth grade. You're still a child. Your body is changing, your mind, your hormone, your emotions, responsibility, all of these things are... You're just starting to come into yourself and you receive this diagnosis at such a tumultuous point in your life. How did that affect you personally, socially at school?

Kiara Mowat: 11:16 I didn't let myself feel the emotions or deal with the emotional aspect of being diagnosed with epilepsy. I didn't realize that having such a large diagnosis like that, it does become a part of you. And I didn't deal with that at all. So I just, I pushed it away. And as if I was almost embarrassed of it and I was ashamed of it and slowly and slowly, throughout high school, it would affect my mental health. And I would just not really talk about it. And I knew that it was affecting my mom. And she would just say to me, like, "Why aren't you dealing with it? Why aren't you talking about it? It's odd that you aren't." And I was like, "I don't know." And I guess I was just so distracted with everything that was going on and I was just so, I guess, embarrassed or ashamed of it.

Kelly Cervantes:	12:27	Now, did you share with your friends that you had epilepsy? Did any of them ever see you have a seizure?
Kiara Mowat:	12:34	Yeah, my closest ones, they did know. They didn't see me have seizures, but they did know of it. But I would never share with people that I've had epilepsy, but now that I've reached university, I'm no longer embarrassed of it. People know now. And I always share on my Instagram awareness of epilepsy and I never used to do that before.
Kelly Cervantes:	12:58	I think that what you're talking about is acceptance. Acceptance of this diagnosis and that it's a part of your life. And so it makes a lot of sense that you would feel stronger and healthier once you owned and accepted this diagnosis and moved forward in your life with it. Were you able to request accommodations in school? Did the seizures affect your schoolwork?
Kiara Mowat:	13:30	Yeah, they really did. It's interesting because you take medication to help your seizures, but it's like your medication also in turn it affects you in another way as well. So my medication, it makes me extremely lethargic. I get awful headaches. My mood is just constantly down all the time because of my medications and my memory now is just awful with every single seizure that I have. And so, I did receive accommodations throughout high school and now in university. Thank goodness. And I'm extremely grateful for of that.
Kelly Cervantes:	14:16	Now, I know that your mother was strongly encouraging you to join a support group. Can you sort of talk to me about your journey to joining the support group and your resistance to it and how it eventually helped you?
Kiara Mowat:	14:34	So what actually happened was I had a really great teacher throughout high school. Her name was Ms. D Gimarino and her sister actually has epilepsy and she's a lawyer. And I was like, "Oh my gosh, I want to go into law. And I have epilepsy." I was like, "Oh my gosh, that's so cool." And she told me that there's an epilepsy support group. And I told her, I was like, "No, I really don't want to do. I don't think I'm ready." And then she told my mom about this support group. I was like, "Oh great." I wasn't great in intervention. And then my mom said, "Look, I really want you to do this support group." And I was like, "No, I really don't want to sit in like a circle with all these people with epilepsy and hold," I thought we were going to hold hands and sing kumbaya.
Kelly Cervantes:	15:36	Sing kumbaya.

Kiara Mowat:	15:36	Exactly. Sing kumbaya or something like a mantra. I did not want to do it. And then my mom said to me, "If you do this, I will get stuff for you off our Amazon wishlist." And I was like, "Okay, count me in. I'm going to do this." And she's like, "You just have to do five sessions every Wednesday." And so I did it and I ended up going back and back again, after the five sessions was up and I ended up building connections with people who were in the support group. And I loved hearing their stories about their diagnosis with epilepsy. And I was just able to connect with people who have epilepsy. And I was never able to do that ever, because I've never... The only person in my life who I know in person that has epilepsy is my grandmother. And she has the same epilepsy as me.
Kelly Cervantes:	16:36	Oh wow.
Kiara Mowat:	16:38	Yeah. However, she doesn't experience seizures anymore because her medication worked off the bat. So in some ways we've been able to understand each other, but in other ways, no, because she doesn't experience seizures anymore.
Kelly Cervantes:	16:53	Out of curiosity, does she take the same medication that you do?
Kiara Mowat:	16:58	No, she doesn't. She doesn't. Yeah. Her medication affects fertility and I want to have children in the future. And so I think that's also a struggle that women with epilepsy face. So it's either control your seizures or can't have a family in the future.
Kelly Cervantes:	17:22	The quality of life considerations can be pretty intense, especially to be making them so early in your life. But I do hope that the epileptologist that you meet with next has other ideas of other medications and things to try. And there are certainly so many medications available that do not affect fertility or can be taken up until the time that you are looking to have a child and then you can transition to another medication. There's just so many options and possibilities out there. I do have so much hope that there's still a treatment out there that can work for you. As we talk about how in this epilepsy journey that you are, although I'm sure it doesn't feel that way after battling seizures for four years, but you are already making a difference and growing into your advocacy through awareness. And I want you to tell us about that. The different ways that you have found to bring awareness to your community.
Kiara Mowat:	18:32	I think that awareness, it just starts with basic conversations with your friends and your family. If you don't know where to start with awareness, I think that's just one basic way that you

		can begin bringing awareness for the community. Especially with epilepsy because so many people don't know about it. And it starts with just educating your family and your friends and the community around you, and then using your social media as a platform. Social media nowadays is such an amazing tool to reach more people around you. Also, just events like Purple Day and just Epilepsy Awareness Month, like in Canada, March.
Kelly Cervantes:	19:17	I know you started a Purple Day at your school, or the celebration of Purple Day.
Kiara Mowat:	19:24	Yeah. What's so interesting is that when I was diagnosed and I told the people in my... I told my friend group. I went to a really tiny all-girl school. There were 47 people in my graduating class. So everybody kind of knew, but no one really talked about it. I never realized how supportive they were of me until Purple Day in grade 12. When I decided to host it in March, I was like, "Okay, guys. I'm doing this." And everyone was like, "Yes, we're there." And everybody wore purple. It was like a sea of purple within the school. And it was just so much support and people were coming up to me and they wanted to talk about it. They wanted to talk about my experiences. They wanted to know and they wanted to be more educated. And I think that I was so blinded. When I was first diagnosed, I was so blinded by my shame and my embarrassment that I never realized how much support I was surrounded by.
Kelly Cervantes:	20:38	You're in college now, which is awesome. And living away from home. How has that transition been moving away from your mom who has sort of overseen a lot of your medical care up to this point and being in college and having to get new accommodations? What has that transition been like for you?
Kiara Mowat:	21:03	Honestly, it's been so difficult living without my mom. And especially actually my brother. He's three years younger than me. He is in grade 10 now. And my brother has been with me... When I was living at home, he's been there for every single seizure. You get emotionally attached to the people who are always there for you during your seizures. And moving out, I got so terrified because my brother, he has always been there for me during my seizures. And I remember having my first seizure outside of home, I was looking for my brother's face and I couldn't... I was like, "Where are you?" I was like, I was looking at my roommate's faces. And I was like, "None of you are my brother." And it's interesting because the people who support you during your seizures and who are around you, they're with you through this journey.

Kelly Cervantes:	22:01	The family is amazing. And epilepsy siblings are something else. I certain saw it with my own son. Now, were your roommates accepting and understanding and you educated them on your seizure plan and all of that?
Kiara Mowat:	22:20	Yeah. So I live with nine other girls and one cat. So there's all of us. And so they've been extremely accepting of me. And when I was coming into the house, when I signed my lease and everything, because I don't live in residence, I was so terrified. It's scary because when you're living with new people, you don't want to feel like a burden to them. And I've realized that I'm never an inconvenience to people. And people with epilepsy, you should never feel like a burden, because honestly and truly you're not. You can't control your seizures and you can't control your diagnosis. And no matter what, the people who surround you and who live with you, they will constantly support you and accept you. And if they don't, then you shouldn't even have them in your lives. And no matter what, you will find someone who will accept you completely and whole as you are.
Kelly Cervantes:	23:32	It's beautiful, beautiful advice. And I think probably something that a lot of people need to hear. So how was the transition academically? You were able to get accommodations in high school. Was the university as willing to work with you on accommodations?
Kiara Mowat:	23:51	Yeah. So finding the accommodations, it wasn't hard like finding my disability coordinator. That was pretty straightforward. But I remember my stability coordinator, her telling me, she was like, "You're my first student with epilepsy." And I said, I was like, "Oh, okay. That's interesting."
Kelly Cervantes:	24:16	That's surprising to me.
Kiara Mowat:	24:16	Yeah. That was surprising to me too considering I don't think that epilepsy necessarily is something that's so rare because I've met a few people.
Kelly Cervantes:	24:30	One in 26. It's not rare at all.
Kiara Mowat:	24:33	Yeah, exactly. And so in my head, I was thinking, "You work with a lot of students, that's kind of surprising." And she said, "So we can navigate this together." And I was like, "Okay." That kind of made me nervous a little. And so, so far... How do I put this? I don't think that the accommodations that have been set out for me have fulfilled my needs in the way that I need them to. Professors and TAs, they don't know. They don't know the

		severity of it and everything that encompasses epilepsy. And so, because they don't know, they don't know how to help students. And they don't know that if I... I don't think that they take it seriously when I tell them I can't come for this tutorial because of this migraine. They just think probably like, "Oh, it's a headache." Or, "Oh, she's probably just skipping or something like that." It is disappointing. But you kind of have to learn how to navigate the world when things like that happen.
Kelly Cervantes:	25:51	Well, I do hope that that piece of it gets better for you. You've experienced so much and you've grown so much. What advice do you give to other teenagers who are newly diagnosed or navigating an epilepsy diagnosis in high school and making that transition to college? What advice do you give them?
Kiara Mowat:	26:18	I think that's a really hard thing because everybody's so different. My biggest advice is, I think, to lean on the people around you, because you definitely cannot do it alone. It's really hard. It's a really hard thing. Even if your medications are controlling your seizures, and especially if your medications or your treatments aren't controlling your seizures. And having support, having a community around you is so important. And it is so vital because you definitely cannot do it alone. And that's something that I honestly, I learned it the hard way you. Because all the emotions, everything that I should have dealt with when I was first diagnosed, I'm dealing with it now. And everybody's journey is different, right? Nobody's epilepsy is the same. Nobody's journey is the same. It's obviously going to be very different and specific to the person. Even if you feel ashamed or embarrassed, it definitely isn't something to be ashamed or embarrassed about. It's just a part that you need to accept in your journey. And then once you do, you can learn from other people and you can share that with other people.
Kelly Cervantes:	27:40	Kiara, you are wise beyond your years. And I so appreciate you sharing your journey and your experiences with us. It is a brave thing to do. You have to have courage to be able to do that. And I am just so appreciative to you for doing that because you will help kids who are walking a similar path to you to know that it's going to be okay. And, you've done it. You've survived. Here you are. And so thank you so so much.
Kiara Mowat:	28:17	Thank you. Thank you so much.
Kelly Cervantes:	28:22	Thank you, Kiara, for sharing your experiences growing up with epilepsy and for your insights into the challenges of living with epilepsy as a college student. As we noted during our conversation, Kiara is one of the 30% of people with epilepsy

who unfortunately do not gain seizure control through current medications. This is why CURE Epilepsy is dedicated to funding patient focused research to find a cure for epilepsy. You can help us in our mission by visiting cureepilepsy.org/donate. Through research there is hope. Thank you.

Legal Disclaimer: 29:02 The opinions expressed in this podcast do not necessarily reflect the views of CURE Epilepsy. The information contained here in is provided for general information only and does not offer medical advice or recommendations. Individuals should not rely on this information as a substitute for consultations with qualified healthcare professionals who are familiar with individual medical conditions and needs. CURE Epilepsy strongly recommends that care and treatment decisions related to epilepsy and any other medical conditions be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.