

What to Expect When You're Expecting as a Woman with Epilepsy

Seizing Life Episode 20 - Transcript

Kelly Cervantes: [00:00](#) Hello. I'm Kelly Cervantes, and this is Seizing Life.

Kelly Cervantes: [00:13](#) On today's episode, we're taking a look at what it's like to manage epilepsy while pregnant with Caroline McAteer. She is the Associate Director of Employer Engagement and Partnerships at DePaul University Career Center. Caroline is also the past President of the Board for the Danny Did Foundation. In addition, she is the proud mother of her nine year old daughter Nora, and is here today to talk about the challenges epilepsy presented during her pregnancy. Caroline, thank you so much for coming to chat with us today.

Caroline McAteer: [00:42](#) It's my pleasure. I'm so excited to have our conversation and talk about this.

Kelly Cervantes: [00:47](#) Tell me a little bit about yourself.

Caroline McAteer: [00:48](#) Sure. I live in Chicago. I work at DePaul University, and the pride and joy of my life is my nine year old daughter Nora, who's in fourth grade.

Kelly Cervantes: [00:58](#) I love that name.

Caroline McAteer: [01:00](#) She just brings so much joy to us. Every day I look at her and quite honestly, I'm so thankful that I was able to get pregnant and have a healthy child. I probably think that more than your average parent, just because I knew that it was possible that we wouldn't be able to.

Kelly Cervantes: [01:23](#) Let's dive right in and talk about that.

Caroline McAteer: [01:25](#) Sure. Sure.

Kelly Cervantes: [01:26](#) You have epilepsy?

Caroline McAteer: [01:27](#) I do. I've had it since I was 11.

Kelly Cervantes: [01:29](#) Since you were 11. Talk to us about your journey with epilepsy through the years, being diagnosed and how that's impacted your life.

Caroline McAteer: [01:37](#) Sure. Yeah. I was diagnosed at 11. They don't know the cause. My parents just were my biggest, of course, supporters, found the best doctors. If the doctor wasn't nice to us, they left that doctor and we found another doctor. They really taught me-

Kelly Cervantes: [01:53](#) Good parental advocates.

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- Caroline McAteer: [01:53](#) Yes, they really taught me how to do that for myself. I kept it a secret until I was about 35 from everybody but close friends and family, because I didn't want people to ever think Caroline with epilepsy, or Carolina has seizures. Or, I didn't want them to think, "Oh my God, is she going to have a seizure and start convulsing around us?" It was easier for me to deal with this disease to just keep it to myself. When I was about 36, I sort of came out and decided ... I got involved with the Danny Did Foundation, and someone wrote a story about my living with epilepsy. I accidentally put it on Facebook and hit public, so people from college and all parts of my life realized, "Wow, she has epilepsy. I never knew that." Now I tell everybody because I think the more we talk about it, the less stigma will be.
- Kelly Cervantes: [02:48](#) I could not agree more.
- Caroline McAteer: [02:50](#) Me either.
- Kelly Cervantes: [02:50](#) I always sort of preface that with it's much easier for me to talk about the epilepsy in our lives because my daughter is not going to have a career. She is not going to have a romantic relationship. There's none of these pieces in her life because it has so significantly disabled her that we really have to worry about that stigma for her, but it's out there. I am always just so in awe and so impressed and so appreciative of the advocates that are out there, the people with epilepsy who are sharing their stories because it is ... Your story, I think, is one of those that is ... It's really important for people to understand that there is just this incredibly wide spectrum from my daughter to a incredibly successful woman who is thriving with a family.
- Caroline McAteer: [03:43](#) Yeah.
- Kelly Cervantes: [03:44](#) Did you always want to be a mom?
- Caroline McAteer: [03:46](#) Yes.
- Kelly Cervantes: [03:48](#) You are on meds. I guess I also want to know ... Are your seizures controlled by the meds?
- Caroline McAteer: [03:53](#) Yeah, Tegretol and Lamictal. I've been on those two drugs for 20 years. Well, I had a temporal lobectomy in 2004 so that's actually part of the story. I had that surgery with the hope that I would come off my medication.
- Kelly Cervantes: [04:09](#) Okay.

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Caroline McAteer: [04:09](#) Surgery wasn't 100% effective, so I had to stay on the meds.

Kelly Cervantes: [04:13](#) You are deciding, you and your husband, that you want to have children.

Caroline McAteer: [04:18](#) Mm-hmm.

Kelly Cervantes: [04:19](#) How far in advance ... I have to imagine that you were in communication prior, obviously with your OB, but also with your epileptologist. How far prior to getting pregnant did those conversations begin?

Caroline McAteer: [04:34](#) Sure. I actually had a conversation with my husband when we were dating because I thought there's no way ... I mean, there was a chance that I wouldn't be able to get pregnant because women with epilepsy statistically can have a harder time getting pregnant. I asked my husband, boyfriend at the time, "Are you open to adopting children if we had to when we get married?" I cleared it with him so that was always out there that we may need to adopt. As soon as I got married, my epileptologist said, "You need to start taking folic acid." I started taking that right away, even though I knew I wasn't ready to have children yet. And took a lot of it, more than your average woman. I always felt like that was comforting to know, "I'm taking these pills twice a day to just prepare my body for hopefully what's to come." That was probably three to four years in advance of trying to get pregnant.

Brandon: [05:29](#) Hi. This is Brandon from Citizens United for Research in Epilepsy, or CURE. Learn more about epilepsy, pregnancy and contraception at cureepilepsy.org/pregnancy. Now back to this episode of Seizing Life.

Kelly Cervantes: [05:43](#) Did it take you longer to get pregnant, or was that a normal-

Caroline McAteer: [05:49](#) Sure. It was a whole-

Kelly Cervantes: [05:50](#) I don't know what normal is in terms of that.

Caroline McAteer: [05:51](#) Yeah, I know.

Kelly Cervantes: [05:52](#) I feel like that's not a fair way to phrase that, because I think every woman's experience in trying to get pregnant is so drastically different. But were there ... Did you come across complications in trying to get pregnant as a result of your epilepsy? Maybe that's the better question.

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- Caroline McAteer: [06:08](#) I didn't. No, I didn't. And I think God was honestly like, "This girl has been through a lot. I'm just going to make this part of her life easy." But it was a lot of preparing to get to that point. I saw a high risk doctor, a pregnancy doctor to just talk about if I were to be blessed with getting pregnant, what's that going to be like. We tried to come off, or I tried to come off my two seizure meds the year before we wanted to try to get pregnant. I tapered off those very slowly and staying on Lamictal, which is safer than Tegretol. Just staying just on Lamictal alone didn't work because I started having seizures.
- Caroline McAteer: [06:51](#) So I decided, you know what? With my diet and consulting with my doctor, I would rather be on these two medications if I was pregnant and be safe as a mom and keep the fetus safe, then to risk coming off them. Because a lot of people don't want to be on any medication when they're pregnant, and that's very normal.
- Kelly Cervantes: [07:15](#) That's the very first thing that sort of comes to my mind, is you read these mommy blogs or every pregnancy book and they're like the only med you should be taking is Tylenol if that, and don't eat sushi, and don't do this. In order to survive and stay safe, you need these serious anticonvulsive medications.
- Caroline McAteer: [07:36](#) Yeah, yeah.
- Kelly Cervantes: [07:39](#) What did the doctor tell you about that? What was your thought process and comfort level because that's a big piece of this.
- Caroline McAteer: [07:47](#) Sure. So with a high risk pregnancy, we had extra ultrasounds. And so my doctor said, "Here's the extra risk with Tegretol, and here's the slight extra risk with Lamictal." And while they were slight risks in my head, it was double what the average woman's risk of having birth defects were. And that's all I could think of was double. So, I knew that. And one piece of having epilepsy and being pregnant is you have to have a lot of blood work. So my neurologist had me do the blood work once a month in the first trimester and twice a month in the second, and then every week in the third trimester to make sure that my hormones weren't decreasing the effectiveness of my seizure meds.
- Kelly Cervantes: [08:27](#) Of course, absolutely.
- Caroline McAteer: [08:29](#) Right. Before I didn't have to think of that, but hormones affect everything.

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- Kelly Cervantes: [08:32](#) Yes.
- Caroline McAteer: [08:32](#) So as we got closer and closer to the delivery, he really wanted to make sure that it no point where my seizure meds being affected by hormones.
- Kelly Cervantes: [08:42](#) Can that also be a seizure trigger?
- Caroline McAteer: [08:45](#) It's interesting, because some women are more likely to have seizures while they're pregnant because of that. And, some women are less likely to have seizures while they're pregnant because of that. So it's really interesting. As I was getting ready to go through this process and thinking about having children, I remember reading that, and actually it didn't affect me one way or the other with the hormonal effects.
- Caroline McAteer: [09:08](#) I had a few minor seizures, but nothing out of the ordinary. I was in very close contact with my doctors throughout the entire pregnancy, especially my epileptologist, to just make sure he knew anytime I had a seizure, a simple partial seizure that he was aware of. And go have blood work done, and go check on this. So it was really halfway through the pregnancy where I realized there's no way we're going to be able to have two children. And I had that conversation with my husband and said, "I just don't know how we will be able to have two children and me get sleep." And he agreed, which made it a lot easier.
- Kelly Cervantes: [09:50](#) So you touch on something incredibly important right there, which I really want to discuss in that having had two children myself, I know that sleep during the third trimester is challenging to say the least. But, sleep deprivation is one of the biggest triggers for people with epilepsy.
- Caroline McAteer: [10:11](#) Yeah.
- Kelly Cervantes: [10:11](#) One of the biggest seizure triggers. How did you manage that? What did your doctor tell you to do to help you sleep during that third trimester?
- Caroline McAteer: [10:18](#) It's my number one trigger, so my doctor knew that. And so, most nights I have a hard time sleeping because in my head I'm looking at the clock and I'm thinking I need to get that six hours. So on the nights that I couldn't sleep I took Benadryl, and that was safe for a woman to take. So it was nice to know that was on my dresser if I needed it, and I didn't feel bad about taking it because my child's fine and I took Benadryl often.

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- Kelly Cervantes: [10:49](#) Yeah. Do what you have to do.
- Caroline McAteer: [10:51](#) She's okay. The doctor did say that your baby might be a little sleeper. I was like, "Well, I don't think my husband's going to mind."
- Kelly Cervantes: [10:58](#) No.
- Caroline McAteer: [11:00](#) Not a common complaint for new parents.
- Kelly Cervantes: [11:04](#) So you're getting through your third trimester and you're putting together your birth plan. What did that look like? How did avoiding seizures and epilepsy affect how you created that birth plan?
- Caroline McAteer: [11:17](#) Sure. So I knew that when we got to the hospital, everybody who was going to be taking care of me needed to know not just that I have epilepsy, but that sleep is important. And so depending on what time we were to go to the hospital on the day the baby was going to come, it really worried me that what if we're there and I have a 12 hour labor and I'm not sleeping. So, my plan was to be prepared to let everybody know I need to sleep. You need to give me a six hour window of just sleep, at least a few hours of uninterrupted sleep. And it worked where my water broke, we went to the hospital and it all sort of worked out. But telling everybody and being really strict and firm about don't come in and bother me, I need to sleep or I'll have a seizure. So that was the day of [inaudible 00:12:14], and it worked.
- Kelly Cervantes: [12:16](#) You birth your amazing daughter, and now it's time to take her home.
- Caroline McAteer: [12:24](#) Yeah.
- Kelly Cervantes: [12:25](#) And you are now going up against the sleep deprivation of new parents. How did you manage that?
- Caroline McAteer: [12:36](#) Sure. So I talked to a friend who had two children, and she helped me really map it out, and it was really a mapped out process. So my husband was working full time, so he couldn't do all the nighttime feedings. So we worked it out where we had this little table in the guest room, and I had set up all the formula bottles so that in the middle of the night he would just be able to grab one. And while I was sleeping, he would be able to go feed Nora. So I would stay awake from nine to three, and then he would get up at 3:00 AM and be up the rest and I would

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sleep. And so we had shifts, and it meant me taking melatonin on those nights I couldn't fall asleep so that I could get that six hours.

Kelly Cervantes: [13:22](#)

You mentioned something else, which I think is important to note in that you used formula bottles as opposed to breastfeeding.

Caroline McAteer: [13:31](#)

Yeah.

Kelly Cervantes: [13:33](#)

I think there's a lot of stigma around that and a lot of pressure being put on mothers to go the natural way. I think that it's really amazing that you do what works for you, and how you keep everyone healthy.

Caroline McAteer: [13:51](#)

Right. There was no way I was going to add one more pressure to my plate of worrying about getting sleep. And so yeah, I formula fed her. You almost have to if you want to get sleep.

Kelly Cervantes: [14:05](#)

Yeah.

Caroline McAteer: [14:06](#)

And she's fine. She doesn't have allergies, all these stories, but, right. The stigma, if women who say those things knew what it's really like to make decisions and personal decisions-

Kelly Cervantes: [14:19](#)

Well, just listening to you, the amount of planning that went into you having your daughter, you're talking about starting this planning process three or four years before she's ever born. And the in depth planning that had to take place through the pregnancy, your birth plan afterwards This is next level plans that most families don't even consider.

Caroline McAteer: [14:47](#)

Yeah. And one of the other things I looked into was having a night nurse and they're expensive, but I thought between my husband needing sleep to go to work. While my mom and dad were coming every Thursday night to take over the night shows, his parents were going to help, but I felt like we could use a night nurse once a week. But, he didn't like the idea of having anyone coming into the house. So he did all the night feedings.

Kelly Cervantes: [15:08](#)

Wow.

Caroline McAteer: [15:09](#)

But having family help out as much as possible and keeping them on a schedule like every Wednesday or Thursday, knowing someone's going to come and take over. So that you have [crosstalk 00:15:19].

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- Kelly Cervantes: [15:20](#) Yeah. What advice would you give to families who are looking to get pregnant, for women who have epilepsy? What do you wish you had known prior to having Nora?
- Caroline McAteer: [15:35](#) I wish I had known a woman who had been through it and had a healthy baby. My doctor reassured me and told me it was going to be okay and everything's going to be fine. But I wish I had heard from another woman who had a healthy baby and was on her seizure meds. So I just had a conversation with a woman who was in that stage of thinking about getting pregnant. She just wanted to talk to me about it. So, what I would tell any young women who are thinking about getting pregnant and have epilepsy, don't listen to the statistics and don't do research online about pregnancy and epilepsy because you'll read a lot of really scary stories that will deter you.
- Kelly Cervantes: [16:21](#) I think that that is valuable advice for most people who are battling a chronic medical condition. You can find any information on the internet that is going to be terrifying and potentially inaccurate. Lord knows I have gone down Google rabbit holes of hell myself, so you have to have that conversation with your doctor. And knowing that epilepsy is such a unique to the individual condition that, one person's story is not your story.
- Caroline McAteer: [16:52](#) Right. My other advice is if you have to stay on your medication, it doesn't mean something bad is going to happen. Most women who are on their medication have healthy babies. And it's safer, any doctor will say this, it's safer to be on the meds for the fetus than to come off the meds. So I think I would just say that it's possible to get pregnant. It's possible to have a healthy pregnancy and delivery, and you just have to be really organized with the sleeping and have a really good partner. Or a night nurse, or a family member that can be with you every night to do the nighttime feedings while the baby's not sleeping.
- Kelly Cervantes: [17:35](#) Caroline, thank you so, so much for being that woman who is willing to share your story, who is willing to talk about your pregnancy so that the thousands of women out there who are in your shoes feel a little less alone.
- Caroline McAteer: [17:52](#) I hope so.
- Kelly Cervantes: [17:53](#) They've heard someone else go through this and they know it's possible, and I think your story will bring so much hope to so many families out there, so thank you.

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- Caroline McAteer: [18:03](#) It was my pleasure.
- Kelly Cervantes: [18:06](#) It was a pleasure speaking with Caroline today. Managing a condition like epilepsy while pregnant can be so difficult to navigate, and we are grateful Caroline opened up about her experiences. It is a reminder that we can do anything we set our minds to. That is why I am on the board of Citizens United for Research in Epilepsy, Cure. Our mission is to find a cure for epilepsy. That starts by working together to find a solution. Discover different ways you can help in the search for a cure at cureepilepsy.org/get-involved. Thanks.
- Speaker 4: [18:48](#) The opinions expressed in this podcast do not necessarily reflect the views of CURE. The information contained here 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 strongly recommends that care and treatment decisions related to epilepsy and any other medical condition be made in consultation with a patient's physician or other qualified healthcare professionals who are familiar with the individual specific health situation.