# Seizing Life, episode 71
## *Epilepsy and College*
**Guests**
**Eva & Michelle Wadzinski / Ashleigh Henrichs & Caroline Pratt / Christin Godale**
**(Transcript)**

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| Kelly Cervantes: | 00:00 | Hi, I'm Kelly Cervantes and this is Seizing Life, a bi-weekly podcast produced by Cure Epilepsy. |
| Kelly Cervantes: | 00:17 | With students preparing to head back to college campuses, this week on Seizing Life, we take a look at the challenges and successes of students with epilepsy by revisiting several former guests who shared their college experiences and insights with us. In 2019, DePaul University student, Eva Wadzinski and her mother, Michelle, spoke with us about the physical, mental, and emotional stresses of college and offered their advice on resources and potential accommodations for college students with epilepsy. |
| Michelle Wadzinski: | 00:50 | When she finished high school, there was a big discussion at her epileptologist's office, convincing her that she needed to take a year off to get seizure control before starting university. And Eva was really reluctant. She was, I think so many things had been pushed back. So many things had been taken away that now the thought of spending a year dealing with seizure control. |
| Kelly Cervantes: | 01:18 | So did you take that year? Did you push forward? |
| Eva Wadzinski: | 01:20 | I did not. |
| Michelle Wadzinski: | 01:23 | She went part-time. |
| Eva Wadzinski: | 01:24 | Yeah, I went part-time because I get bored very easily. I could not fathom being out of school for a year. |
| Kelly Cervantes: | 01:33 | I just have to imagine that that college application process was significantly different for you than for your peers. What was that like? |
| Eva Wadzinski: | 01:44 | The application was very easy. We just had to talk about an essay about hardships. And I was like, I have a lot of those. So I got in and then I started four classes and my grades kind of just fell down because of how many seizures I was having. I was also weaning off a medication and putting a new medication on. |
| Kelly Cervantes: | 02:07 | And this was not at DePaul. You started at... |
| Eva Wadzinski: | 02:10 | Harold Washington City College. And I started in a community college cause I didn't think I was at the health to go to a four |

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| | | year university. And I also went through two brain surgeries in the process. Yeah. And so, then I started DePaul. I started with four classes. It was not working out well. So I went down to three and it's been better. |
| Kelly Cervantes: | 02:33 | So at some point you decided that you could make that change from the city college to a four-year university. What inspired that change? |
| Eva Wadzinski: | 02:45 | I always have the notion and the mentality, if you want this hard enough, you'll be able to get it regardless of your disease. And so you kind of just have to push forward every day and you end up having to educate your professors, your classmates, you are a student of accommodations because no one seems to know what epilepsy is. |
| Kelly Cervantes: | 03:08 | Which leads perfectly into my next question. What do you tell your professors and how do they respond? |
| Eva Wadzinski: | 03:17 | It differs. |
| Michelle Wadzinski: | 03:19 | We have a letter that we've been giving to every teacher since I don't know, freshman year. And we've modified it, but the same letter, go in and make the modifications, print it out, give it to them, trust that they'll actually read it. |
| Eva Wadzinski: | 03:33 | Yeah, and then I'll have one professor whose like well you were gone but I was gone because of seizures, but they think I just skipped class. Then I have to go to my doctor, to my psychologist, to my student of accommodations, to get everyone in to say, no, this is not because I skipped class, this is because it's unsafe for me to be in class. That's tough when that happens. |
| Kelly Cervantes: | 03:56 | Well, it's creating more stress for you in an already stressful environment. I mean, college is hard, right? And so that additional work has to be tough. What do you tell your peers, your fellow students? |
| Eva Wadzinski: | 04:15 | I don't usually tell them because it's more of a personal thing. Especially if I'm not close to them or they're friends of mine, then it's like, I'm just going to do. But I've had seizures during classes, and then it makes the professor more aware because I don't have tonic clonics unless I'm off of my medications. I have all these other ones that may not be apparent. But, I had a seizure in my math class where my arm convulsed and it |

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| | | actually hit one of the girls and she was like, are you okay? Like they thought I was probably on some drug. |
| Kelly Cervantes: | 04:53 | Which is just so frustrating that that is where the thought process goes because people are so uneducated about seizures. And you talk about student accommodations. What are some of the accommodations that you have requested from your schools? |
| Eva Wadzinski: | 05:10 | I have a longer time for tests; they give me extended time. I have one that if I have doctor appointments or medical appointments that I will get passed for it. Sometimes that happens, sometimes it doesn't. |
| Michelle Wadzinski: | 05:24 | That's not an official accommodation. That's something that's not available through the accommodations' department and we've fought for it to increase the awareness that if she's having a day where she's having 10, 15, 20 seizures in an hour, she needs to come home, take rescue medication, and that puts her out. She can't be in class. Then, some of the epileptologist appointments were if you miss it... You have to keep it because you might not get in for a little while and you just need to be there so we fought for that accommodation. But the extended time for tests is... |
| Eva Wadzinski: | 06:01 | It's very helpful because I might have seizures during classes and it takes me 10 to 15 minutes to be aware. It's very helpful in those situations. I'll have classes where I have seizures and I can't really get back to the lecture right away, and so then you lose that 15 minutes of class. So, what are you going to do, ask them to repeat all this stuff? And then I have short-term memory loss sometimes and sometimes I don't retain everything. So I always have loads of notes written out so I can remember it. |
| Kelly Cervantes: | 06:35 | Yeah. Are there specific things that you would recommend to schools? Different ways that they can better accommodate students with epiplepsy? |
| Eva Wadzinski: | 06:45 | One thing that I try to give people more information that are around my age, are going to high school or going to college, that they don't give you a menu of how many student accommodations you can get. So you have no idea of what's out there for you and you have no idea if it's actually going to apply to your disease, whatever it is. So, I think that's not okay because what if this one's going to very much help you, but they're not going to say, oh, you can have this or you can not have this. |

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| Kelly Cervantes: | 07:14 | Right, to even know what the possibilities are, what you can even ask for. |
| Michelle Wadzinski: | 07:19 | Well, and it's a law that students are protected through primary and secondary school. That law does not extend to college students. That is at the decision of the university and the instructors. The law does not protect you at university level. It does not protect students with disabilities. |
| Kelly Cervantes: | 07:39 | I had no idea. |
| Michelle Wadzinski: | 07:40 | Yeah. I know it was shocking to me, too, when she started down this road at university and I, all of a sudden learned that the same protections from. |
| Kelly Cervantes: | 07:49 | Aside from I'm sure the ADA protects. |
| Michelle Wadzinski: | 07:51 | Yeah, but as far as the educational things. So it's an individual experience at each individual learning institution. |
| Kelly Cervantes: | 08:01 | Huh. So going on this journey, through high school, going to college, now being in college, what tips, what recommendations, what advice do you have for teenagers who are walking the same path as you? |
| Eva Wadzinski: | 08:22 | I would connect with people who are already in school who have epilepsy because they're able to give you a lot more tips and you have an advocate for you. And then also just research a lot about your university, because some have good student accommodations, some have horrible ones. And so you really have to look further than a person that doesn't have a disability. |
| Kelly Cervantes: | 08:47 | So, it needs to be part of your college selection, not just who has the prettiest campus and the best food, but you're really looking at, that's a major decision factor. |
| Eva Wadzinski: | 09:00 | A lot of times, if you have epilepsy or any other disease, your doctors are in one place. For me, I had to find a university in Chicago or in Illinois because I didn't want to change and restate my story every single time. |
| Kelly Cervantes: | 09:15 | I understand that. Yeah. So, you can still get out there, you can still get that college degree, but you also have to respect your limitations. |
| Eva Wadzinski: | 09:25 | Yeah. Always go back to your student accommodations and update them of what's going on because then they can change |

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| | | things for you because it's an ever-changing disease. I think just being resilient about going to these people, going to your professors, because then they will all start understanding a bit more. |
| Kelly Cervantes: | 09:43 | It all boils back to communication. |
| Eva Wadzinski: | 09:45 | And then also I think people need to be aware that you're not going to get judged if you have to take limited classes each quarter or semester, and it's more normal to have to be in school for five years. No one is going to go, |
| Michelle Wadzinski: | 09:58 | At university. |
| Eva Wadzinski: | 09:58 | At university. Yeah. And people aren't going to judge you for it. |
| Brandon: | 10:06 | Hi, this is Brandon from Cure Epilepsy. Did you know that one in 26 Americans will develop epilepsy in their lifetime? For more than 20 years, Cure Epilepsy has funded cutting edge, patient focused research. Learn more about our mission to end epilepsy at cureepilepsy.org. Now back to Seizing Life. |
| Kelly Cervantes: | 10:26 | We spoke with Caroline Pratt and her mother, Ashley Henrichs, about the changes that occur in the parent-child relationship as a child with epilepsy moves away from home to attend college. |
| Kelly Cervantes: | 10:37 | You've gone through high school. You've had this positive environment. Your seizures are still not under control, but it's time to start thinking about college. What is going through your mind when it's time to send in those college applications? |
| Caroline Pratt: | 10:58 | For starters, I did not want to go to a college so close to home. I didn't want to go too far away, but I wanted to go and only be a couple of hours away. Then, I started having more big seizures, and closer together. Of course, I don't have a trigger, so that wasn't really great. And on top of that, I got a scholarship to Carthage and mom was basically like, if you get a scholarship, you're going. |
| Kelly Cervantes: | 11:40 | So I think a lot of parents feel that way. That's a pretty normal parent response. |
| Caroline Pratt: | 11:49 | They were able to give me the accommodations that I needed. |
| Kelly Cervantes: | 11:54 | What were some of those accommodations that you requested? |

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| Caroline Pratt: | 11:58 | Well, for one, I get to live in a dormitory that is typically only for seniors or people who request accommodations.Just cause it's really great, you don't share a bedroom with six people. |
| Kelly Cervantes: | 12:18 | Which is important because you need your sleep. Lack of sleep and stress can be a huge seizure trigger. So making sure that you can get a good night's sleep, which can be very challenging to do in college if I remember correctly. So, that's incredibly important. |
| Ashleigh Henrichs: | 12:36 | She also has academic accommodations and just like her high school, they were very open to that and she has extra time on testing. It was interesting. We had two very different experiences on college interviews and Carthage, as I said, was very open to whatever she needed to be successful. Another college said, I don't think we've ever had anyone with a seizure disorder on campus. I was thinking it's one of 26. So you have. Again, she's been very fortunate to have the support system that she has. As her health is still kind of a question, mark, we really are thankful that her dad and I are both nearby and that we can get to her if needed, but that she can live on campus also. |
| Kelly Cervantes: | 13:32 | Yeah and experience that level of independence and responsibility. So, what is going through your mind as mom? I can't even imagine the sort of anxiety that you have around letting her go and explore this independent world. What are you thinking? What have you learned or what advice do you have to get parents through this? |
| Ashleigh Henrichs: | 14:02 | Well, there's a picture that Caroline loves to kind of make fun of because we took a lot of pictures on move in day and there was one where I'm hugging her and I'm just a wreck. I'm just a wreck and people who didn't know us that well thought, she's going to college in your town that you live in, so, I know you're a little nervous. I think my advice, again, the communication has to be there with wherever your child is going. As far as every housing, academics, counseling has to, everybody has to be on the same page. |
| Ashleigh Henrichs: | 14:42 | Caroline has not been healthy since she started at Carthage. Even move in day, we got a call right after we left, but, she's making her way and she wants to make her way. One of the things we started was an app, a medication app so that we get notified, her dad and I do, if she's not taking her meds. And so pieces like that. But we can't hold her close. That wouldn't be good for her, wouldn't be good for us. She does need to have |

that level of independence. Prefer that she have a cleaner room, but that's on her.

Ashleigh Henrichs: 15:40 The other part that was a little different is that she skipped a grade, so she's only 17 at college. But, again, she's making her way and it's important to her that she does that with limited interference from Mom and Dad.

Kelly Cervantes: 15:57 Caroline, what advice would you give to other teens and kids getting ready to go off to college and what they should be looking for, both in a school, but also navigating that parent relationship?

Caroline Pratt: 16:17 Well, I would say, just be sure to stay close with your family. I found that's what helps me. They're always there to support me. Honestly, the best advice would just be to be yourself. Epilepsy is what you have, it's not who you are and just be you and most of the time, people won't even really notice you have it.

Kelly Cervantes: 16:55 Right. Absolutely. Ashley, what advice would you give to parents as they are navigating this new found freedom for their children? How do you best navigate this next stage of your life and parenting?

Ashleigh Henrichs: 17:13 I think one of the things that I was very happy and impressed with was that each of her professors emailed her and said, we're aware that you have accommodations. We need you to schedule time with each of us to discuss exactly what we can do to help you. That was big for me as a parent, because I'm out of that, I'm not involved with that and that's Caroline's responsibility now, which was important. So, that role changed with that email. And, I've never been a helicopter parent. I mean, certainly, epilepsy changes things, but my children need to solve problems on their own. Of course this thing is progressive, if nothing was happening then mom would get involved. College is, again, there's a lot more responsibility on the student and there really needs to be.

Ashleigh Henrichs: 18:18 Again, communication is key. I had to be comfortable with what I was hearing and seeing before we committed to Carthage and I think that's true, whether your child's going to a large school or a small school. They have to want to be there and you have to be comfortable with that investment, with the resources available, and then you have to trust. You have to place a lot of trust in the faculty and the staff and your child. Certainly, I don't remove myself from the equation entirely, but it's a different in

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| | | her life, absolutely, and in my life. It's hard, it's hard. It's wonderful. And it's hard. |
| Kelly Cervantes: | 19:11 | Do you get notified with every seizure? |
| Ashleigh Henrichs: | 19:15 | No. Caroline typically will let me know with the larger ones. She had one in class yesterday and that's just a struggle. It's one thing if you're in your dorm room and it happens privately, but it's hard to be in a new environment, have a fresh start, which is what we told her college was, but then still have to deal with it. |
| Kelly Cervantes: | 19:44 | You're still taking your baggage along with you, unfortunately. |
| Kelly Cervantes: | 19:50 | In one of our first remote episodes during the COVID-19 pandemic, University of Cincinnati PhD candidate, Christin Godale, spoke with us about how growing up with epilepsy influenced her decision to pursue a career in epilepsy research and why she became more public about her diagnosis during her college years. |
| Christin Godale: | 20:10 | It was hard growing up with epilepsy. It really was. And it wasn't until I was in college, I started to be more frank with people, and I talked about it. I talked about epilepsy, look, I have epilepsy. This is a seizure. And that was the first time that I remember being an official advocate for the disease and telling people about it. And I think that's what we're here to do, but. |
| Kelly Cervantes: | 20:34 | What made you change your mind to start telling people that you had epilepsy versus keeping it a secret? |
| Christin Godale: | 20:42 | Oh wow. There was this, there were a couple things. But I remember when I was in high school, I had really bad status epilepticus events. I was hospitalized. It was bad, but my neurologist actually encouraged me to start to learn about the disease. They gave me books. I'm in the hospital with all these electrodes on my head and having seizures, but I'm reading about epilepsy. My doctor then invited me to an advocacy event they were having at the hospital. I was just volunteering and I came into contact with this young boy and he obviously had epilepsy; he was like nine or something. He looked at me and he's like, "you have epilepsy?" And I responded, "Yeah." And then he began to ask me all of these hard questions like, can you get married? Can you have a job? Can you go to school? Can you have friends? Can you like do all this stuff? At the time I wasn't sure, but of course I said yes. |

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| Christin Godale: | 21:59 | After that event in my life, I began to reevaluate how I viewed the disease and that really started my advocacy journey. In college, that's what made me so open about it. And, as a blossoming neuroscientist who wanted to study the disease, it wouldn't look too great if I started to hide it from the very beginning of my academic journey. |
| Kelly Cervantes: | 22:29 | Was there a difference in the way that people responded when you told them upfront in college about the epilepsy versus how they responded in middle school and high school? |
| Christin Godale: | 22:39 | Of course. Yeah. I think it also has to do with the level of maturity of my peers from one time to another, but everyone was very accepting of it. If I had a seizure, they were fine. They called, they followed my seizure action plan and they called my mom or they called the ambulance when needed. And no one was really afraid to work with me or be my friend. I was very thankful for that. Well, versus in high school where I didn't tell anyone and when I had a seizure, it was a totally different reaction because they didn't know. And it was like surprise. |
| Kelly Cervantes: | 23:22 | We've spoken with several college students who have epilepsy and going through that experience. What was college like for you? Did you ask for accommodations? What was your college experience like? |
| Christin Godale: | 23:41 | I actually didn't ask for accommodations in college. I actually didn't receive accommodations in grad school until I had a status epilepticus event in 2017. And the reason being is because I think I was too proud and I didn't want people to think, oh, you have epilepsy and that's why you need this extra time. And I just didn't want anyone to think that because I still, to this day, I believe I can do everything and anything as well as someone who doesn't have epilepsy. But, that really hurt me at the end because I had some problems with accommodations for some classes and since I didn't have all the paperwork filled out, I had a hard time. So, looking back, I would definitely tell any college student to go to your accommodations office immediately and just fill the paperwork out. Don't be like me, don't wait, and don't let your pride get in the way. It just doesn't matter in the end. What matters is you doing well in school, getting your grades and then going off to wherever you need to go. |
| Kelly Cervantes: | 25:01 | Thank you to all of our guests who shared their insights and experiences navigating college with epilepsy. The college years are a time of significant transition for any family. But for those who are impacted by epilepsy, it's also fraught with new, |

emotional and physical challenges. If you are one of those students or families impacted by epilepsy, we hope this episode has provided some helpful information and insights to consider as the new school year begins. Epilepsy patients and their families are at the heart of the patient focused research that Cure Epilepsy has promoted and funded for 23 years. Our goal is to advance new therapies, to promote seizure reduction and freedom for patients and their families. If you would like to support Cure Epilepsy's research, please visit cureepilepsy.org/donate. Your support and generosity are greatly appreciated. Thank you.

Speaker 6: 26:01 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.