

Seizing Life, episode 62
Growing Up Alongside a Sibling with Epilepsy
Guests: Emma Cardwell and Nathan Bliss
(Transcript)

Kelly Cervantes:	00:01	Hi, I'm Kelly Cervantes, and this is Seizing Life, a bi-weekly podcast produced by CURE Epilepsy.
Kelly Cervantes:	00:19	Today, I'm happy to welcome Emma Cardwell and Nathan Bliss to the podcast. Emma is a student at Middlebury College where she is a neuroscience major on the pre-med track. Nathan is a student at Texas A&M University, studying bioengineering. Emma and Nathan are recipients of CURE Epilepsy's Education Enrichment Fund Scholarship, which is given to those living with epilepsy, their family members, or caregivers.
Kelly Cervantes:	00:45	Both Emma and Nathan have grown up alongside a sibling with epilepsy, and they are here today to talk about their experiences and the impact of having a sibling with epilepsy. Emma, Nathan, thank you so much for joining us today to talk about your siblings and your sibling experience. To kick things off, I want to hear about your siblings. Emma, tell me about Abby first, and then Nathan, I'd love to hear about Charles.
Emma Cardwell:	01:13	Yeah, so I'm an older sister to my middle sister, Abby. When she was around two, she was diagnosed with epilepsy. She has a suspected mitochondrial disorder, but that hasn't been confirmed with genetic tests yet. But this results in her having other health conditions like poor muscle tone and intellectual disability and kidney problems, so she has multi-system organ issues, but she definitely takes it like a champ.
Kelly Cervantes:	01:45	Nathan, what about Charles?
Nathan Bliss:	01:46	Yeah, so Charles is a couple years older than me, but Charles was first diagnosed with autism at a young age. And then, when he was seven, the onset of his epilepsy came. He was later diagnosed with the rare genetic disorder, Phelan-McDermid syndrome. And Charles has Lennox-Gastaut epilepsy, a severe form of treatment-resistant epilepsy.
Kelly Cervantes:	02:07	So I think it's interesting we have an older sibling and a younger sibling here, which is going to, I think, offer a different perspective. When did each of you first learn about your sibling's epilepsy? Nathan, I'll let you kick us off there.
Nathan Bliss:	02:25	Yeah, so Charles' first seizure was when he was about seven years old, and I must've been about five years old then. But he had one grand mal seizure and it lasted about 40 minutes. And I

remember the paramedics came to our house, and it was a really scary experience for our whole family, and I don't think my parents really knew what was going on.

Nathan Bliss:	02:46	But after that, he had a series of more grand mal seizures, and since then, his epilepsy has gotten significantly more severe. There have been days where he's had thousands of seizures, and in the past few days, Charles has had dozens of seizures. But I remember my parents explaining it to me as a mis-wiring in Charles' brain, like a loose circuit was going off, and I think that made a lot of sense to me. Yeah, I think that was a good way to explain it to me.
Kelly Cervantes:	03:15	Emma, what about you with Abby, and when did you first become aware of her epilepsy, and how was it explained to you?
Emma Cardwell:	03:24	So I was about three years old, so I don't really remember it, but I remember it being explained to me that pretty much all her entire body was shutting down except for her brain, which was being overactive. And I just remember, maybe when I was a little bit older, that, just looking out the window and hearing the sirens, I could sense my parents' stress. And I just saw my little sister being carted off on a stretcher with all these paramedics and EMTs around her. It was definitely a really scary experience.
Kelly Cervantes:	04:05	I can only speak to it from the parents' side, but I can imagine, as a child, the difference being that you have a lot less information to work off of. How did your sibling's epilepsy affect your family?
Emma Cardwell:	04:21	Yeah, so my family was very stressed all the time. We never knew when a seizure would hit. It was unpredictable. When she first started having seizures, they were uncontrollable. Just like in Charles' case, she was having hundreds, and they would always cluster, they would always be grand mal seizures. And she would have to go to the hospital because the rescue medications didn't work, so we were definitely always on edge, really traumatized, also. We were told that the doctors had abandoned hope and that she might not make it a lot of times by multiple doctors.
Emma Cardwell:	05:04	But it definitely brought me and my extended family together. They really took care of me when my parents couldn't be there for me and with Abby in the hospital. So it brought us together and also just showed us who we could really trust, so I guess that was a good thing that came out of it.

Kelly Cervantes:	05:24	Absolutely. And what about in your family, Nathan?
Nathan Bliss:	05:27	Yeah, so I think from the onset of Charles' epilepsy, our really big family concern really became caring for Charles and trying to get his seizures under control. And it was everything from, he was starting to have a wheelchair at home, and Charles had to wear a helmet for a period of time because his drop seizures were so bad. And I mean, there were periods of time where Charles was in the hospital for hundreds of days. And I know my family was always having to focus on him, and we had hired nurses and attendants to help take care of him, and someone always had to be with him at all times in case he had a drop seizure.
Nathan Bliss:	06:02	But I was often left fending for myself. My parents would be at the hospital, or parents would be at work and taking care of Charles. And so, oftentimes, I would stay with friends and family members. I'd stay at my grandparents' house for a long time. I learned a lot of responsibility growing up during that time, trying to take care of Charles myself and take care of myself when my parents were taking care of Charles, so it had a big impact on our family.
Kelly Cervantes:	06:29	How did having a sibling with epilepsy affect you personally? Were there things that you couldn't do? Did it affect your social situation at school? What did those personal effects look like?
Nathan Bliss:	06:42	I would say, growing up alongside Charles, it was hard to see his epilepsy. I had grown up with it all of my life that I can remember. But it was really when I started hanging out with my friends and I realized that their siblings weren't like Charles, is when I really started to recognize that Charles was different and he was dealing with something that other siblings weren't.
Nathan Bliss:	07:04	I remember very clearly, my mom telling me about a time that I had spent the night at a friend's house and I'd come back and I'd told her how, "Oh, my friend and his brother were fighting, and I was wondering..." I was like, "Why don't Charles and I do that?" And so, I think that was kind of a moment of realization that Charles was very different than other siblings.
Nathan Bliss:	07:22	But Charles went to school with me in high school, and I remember a lot of the kids would see him wearing a lacrosse helmet. He wore a lacrosse helmet for a long time that had a face mask because he would fall from his drop seizures and we wanted to protect his face. And I remember kids in high school being very judgemental, and pointing, and saying, "Why is he wearing a helmet?" And a lot of people would say, "Oh, that's

Nathan's brother." I think I wanted to distance myself from that for a long time. I was embarrassed to see that kids were judging Charles for that, and it took me a little bit to learn that I shouldn't be embarrassed of that, or that Charles can't defend himself in a situation like that and there's no one to stand up for Charles but me.

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| Nathan Bliss: | 08:04 | And so, I did. I quickly learned that it's not right of me to be embarrassed or want to distance myself from Charles' situation, and that I really embraced being his brother, and that he was unique in that way. So I think I really learned who my true friends were because they were able to communicate with Charles, and look past that, and not judge him for being in a wheelchair or having to wear a helmet to school. And I think it really taught me a lot about my friendships and about how I can embrace Charles' differences in public, in school. |
| Kelly Cervantes: | 08:43 | I bet you taught a lot of people lessons that they still carry with them today. Emma, what about you? How did having Abby for a sister affect you personally, growing up in school, and activities? |
| Emma Cardwell: | 09:01 | Yeah, so similar to Nathan, when I was younger, especially, my friends would... Whenever they came over, they would be like, "Oh, why can't your sister talk? Why can't she walk properly? What's wrong with her?" And I was embarrassed. I was like, "I don't know, she has something wrong with her brain." And yeah, so similar to Nathan, I was embarrassed, just because she was different. And the younger kids, being young, they have no filter, so they really made me aware of how different she was. But as I got older, I obviously came to embrace those differences, and so did the people around me, and that's why we all love her so much. |
| Emma Cardwell: | 09:49 | But I definitely, because of her epilepsy and the unpredictable nature of the disease, you can't really plan ahead, so I had to miss a lot of play dates with friends, I couldn't go to the movies, like most young kids do. I never knew who was going to pick me up from school, so school took the back-burner. And then when Abby relapsed, when I was older, and started having bad seizures again, I kind of had to prioritize her, and then taking care of my youngest sister, picking her up from school and taking her to her extracurricular activities. So again, really, the only thing I was able to do at that time is school. And then I had a job, which I also had to miss a lot of work to take care of my youngest sister, or to relieve my parents from sitting by Abby's side at the hospital. |

Speaker 4:	10:46	Become an agent of change in the epilepsy community, apply for CURE Epilepsy's 2021 Education Enrichment Fund Scholarship. We are currently accepting applications from those living with epilepsy, family members, or caregivers for this scholarship, supporting coursework in your chosen field. Applications are due April 15th, 2021. For more information, or to apply, please visit our website at cureepilepsy.org/scholarships , or contact us at scholarship@cureepilepsy.org .
Kelly Cervantes:	11:19	I can only imagine that, at times, there was likely some resentment there for both of you. I think that that would be fairly natural. But I'm curious to hear how your relationship is with your siblings today now that you're a bit older and you have some perspective and a little life experience under your belt. Emma, how is your relationship with Abby?
Emma Cardwell:	11:44	Yeah, so now, Abby and I are inseparable. [inaudible 00:11:48] FaceTime because we're always on FaceTime whenever she has a free time in the middle of her day, or in the middle of my day, she'll just call me. And she's my best friend. I could just talk to her for hours. She's such an inspiration to me, also, even though she's my younger sister. I look up to her every day, and she inspires me every day to keep going to school and to stay positive, so she's one of the biggest role models in my life and my best friend.
Kelly Cervantes:	12:20	I love that. Nathan, how is your relationship with Charles?
Nathan Bliss:	12:25	You had said something about resentment, and I think that's a common thing I see with a lot of siblings with other siblings with disabilities. And I think for a long time, I did feel that way. I was like, "Yeah, this is really unfair that I have to be embarrassed when kids come over to our house, or my house, to play with me," and then I would be embarrassed about his nurses, or his medical equipment, or his attendants being there. And so, I never really wanted to have kids over to our house, and I did feel a lot of that resentment for a while, and it took me a while to get over that and see how stubborn and selfish that was.
Nathan Bliss:	13:03	And I think my perspective really changed on that, and I can't believe I thought that back when I was younger. But I'd say, today, Charles and I, our relationship is good now, and I think... Charles is non-verbal, so our form of communication is a little bit different than most siblings, and so we don't talk traditionally, but we do share experiences, and that's our form of communication. Charles loves to go on Jeep rides, so we'll

take him out in the Jeep, and we'll put the top down, and that's one of his favorite things to do.

- Nathan Bliss: 13:36 We'll do other activities together, and I know he's enjoying it. He'll be smiling, and so that's really our form of communication. And being in college, it's been a little difficult to see him so often, but I'm able to see him more now, and I can go home, and see my family and Charles. And so, our relationship has changed over the years. When Charles used to speak when he was younger, he had a pretty solid vocabulary, but he's slowly lost that ability to talk over time, and I think we've definitely grown closer through those years.
- Kelly Cervantes: 14:09 I don't imagine that spending the last year plus in a global pandemic helps when you have a medically complex or fragile sibling at home, and being able to connect with them personally.
- Kelly Cervantes: 14:23 So I think that it's incredibly interesting that both of you have decided to go into a medical field, medical profession. Can you explain what led you in that direction, and what you are currently studying and hope to do for a career?
- Emma Cardwell: 14:44 Yeah, so I'm now a senior at Middlebury College, and I'm going to graduate with a bachelor's degree in neuroscience and a minor in global health. So the neuroscience piece definitely comes from growing up with a sibling with epilepsy. When I first kind of took a dive into science and we learned about the brain, I just was really fascinated, and I had this really personal connection to the brain and disorders of the brain.
- Emma Cardwell: 15:17 So that's really what triggered my interest in neuroscience, and then seeing all the doctors and their compassion and hard work, and just really inspired me to want to do the same thing. And I saw how much they helped me and my family and my sister, and really changed her life, and saved her life too, and I really hope to do that for other people.
- Kelly Cervantes: 15:46 I think you're going to do an amazing job. Nathan?
- Nathan Bliss: 15:49 Yeah, so I remember my mom telling me a story when Charles was in the hospital for a while, that there was a resident that was visiting Charles, and on her last day of rotation, I think she broke down crying and was like, "I've never seen a case like Charles', where it's been so helpless and there's just so little that we can do to control his seizures." And I think that really sums it up well. I think a big struggle of our family has been the

frustration from how little we can do. I mean, our biggest goal has really been trying to improve Charles' quality of life and control his seizures. And Charles has been on hundreds of seizure medications, and he's had brain surgeries, and he's had a device implanted in his chest, a vagus nerve stimulator, to try and control his seizures, and he's tried the ketogenic diet.

Nathan Bliss: 16:40 And it all worked for a little bit, and then his seizures returned, and so he's been on this endless cycle of trying new clinical trials and experimental drugs. And so, I think that frustration that our family has shared has really inspired us all to want to do everything that we can in our power to help people like Charles. And Charles had a lot of medical complications. I mean, he had geneticists, epileptologists, neurologists, I mean, every kind of doctor you can imagine. And I was around them all the time, and I think being surrounded by those people was absolutely inspiring. I think seeing all the work that they were putting in to help individuals like Charles, it really inspired me and motivated me to do the same.

Nathan Bliss: 17:27 In the yearbook, I have a picture of me in second grade saying, "When I grow up, I want to be a neurologist," and I hardly knew what it was back then. But it's still true, and to this day, I still want to be a neurologist. So right now, I'm a junior at Texas A&M University, and I'm studying biomedical engineering. I'm hoping to go to medical school after this, and I would like to do neurology and neuroscience, so hopefully I can do some research as well. I've seen the power that clinical research has, and Charles has been involved in a lot of clinical research, and that is certainly what I want to do in the future. So 100%, Charles has inspired me and motivated me to go into this field. And I've met tons of siblings similar to Charles that have dealt with really challenging struggles, and that's what I want to do.

Kelly Cervantes: 18:17 That seems to be a strong, common thread, and goodness knows we need all of the neurologists, epileptologists, and researchers that we can get in this world, so I'm grateful to both of you for starting to journey down this path. What advice do you have for other siblings of children with special needs or epilepsy that you'd like to share from your past experience?

Emma Cardwell: 18:46 So I would say having a support network is the most important thing, both for you and your family and your sibling, as well as you being a good support system for them. And it's really important to try and stay hopeful and positive, despite all these traumatic things and maybe bad news that you're receiving a lot of the time. But just remember that someone needs your positivity and hopeful energy.

Emma Cardwell:	19:17	Also, I would say being an advocate is really important, as well. Just always stand up for your sibling. Like we were talking about earlier, it is really hard growing up, not getting the attention from your parents, and you do feel a little resentful and jealous, and looking back, it is really... I'm ashamed that I ever thought that. But just try and keep in mind that it's probably 10 times harder for your sibling and what they're going through than it is for you.
Kelly Cervantes:	19:52	Now, I want to follow up there because I'm curious, being a parent, having a neuro-typical child, and having my daughter who had epilepsy and a multitude of other medical complications, are there certain things that your parents did that worked well, different tricks that you remember, that you were receptive to? And if not, that's completely okay. I'm just curious.
Emma Cardwell:	20:21	I think they would try to find things that I like to do and do them with me, like taking me out to get ice cream, or to the park, or something, and just trying to find that one-on-one time with me, especially just because, one minute, I was an only child and got all the attention, and the next minute, I had a sister who had all the attention. So I think they tried to do that as best they could.
Emma Cardwell:	20:49	Other than that, I spent a lot of time with my cousins who are a similar age to me, and so I got a lot of attention from my aunts and uncles. But I think just trying to make that one-on-one time is really important because it just reminds the other sibling that they're also important, and that they're being seen and being heard, too.
Kelly Cervantes:	21:10	Nathan, same question to you. What advice do you give to other siblings out there? And also, were there any tips or tricks that your parents used to help relieve some of your resentment or still make you feel special, even considering the circumstances?
Nathan Bliss:	21:29	Yeah, so I guess the advice that I would give to other siblings is that you're not alone there. I've met a lot of siblings, and like we had mentioned earlier, all of them seem to be very inspired and motivated by their siblings. And so, I would say, use that momentum and use that motivation to do something, and make a difference, and impact the lives of people like your siblings.
Nathan Bliss:	21:51	I know it's easy to feel resentment towards your siblings, and it's important to remember that this isn't something that's in their control, and a lot of times, there's no one to stand up for

them except for you. And I think it's a different perspective from the parents, seeing your child grow up. But growing alongside a sibling is a different kind of bond, and it's always important to remember that. I think it took me a long time to see that, and I wish I'd seen it earlier. But know that your sibling is your sibling, and you got to give them the unconditional love that they deserve.

Nathan Bliss:	22:24	To answer your other question too is, with my family, I know I was incredibly grateful. I was always loved. It was easy for me to forget that at times and think that, "Oh, I'm not getting the attention that Charles is getting." But truth is, he needed that attention a lot more than I did. There were times where my parents would have to alternate being in the hospital for weeks at a time, and I wouldn't see them for a long time, and it was easy to feel neglected of that attention. But my parents always did a really amazing job of giving me that attention, and I think... They came to my sporting events all the time, and they would make time to doing activities that I enjoyed, and I think that was really special.
Kelly Cervantes:	23:10	Absolutely. You two are incredible, and we are so grateful for your time, and your energy, your compassion, and your empathy, for sharing your journeys. I think it's going to be incredibly helpful to other siblings out there as well as to parents and families as a whole who are continuously walking a shared journey with both of you, so thank you so much for your time. You're incredible.
Emma Cardwell:	23:39	Thank you for having us.
Nathan Bliss:	23:44	Thank you.
Kelly Cervantes:	23:44	Thank you, Emma and Nathan, for sharing your experiences growing up with a sibling who has epilepsy. As we heard from Emma and Nathan, an epilepsy diagnosis doesn't just affect the person with epilepsy, it impacts the entire family. Those impacts can be both challenging and inspirational.
Kelly Cervantes:	24:02	CURE Epilepsy was born out of the challenges faced by families living with epilepsy, and for more than 20 years, we've been inspired by patients, family members, caregivers, physicians, and scientists, to fund research in pursuit of our goal, a world without epilepsy. We hope you help us reach that goal by visiting cureepilepsy.org/donate . Your support and generosity are greatly appreciated. Thank you.

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