

Seizing Life, episode 121
A Teen Uncovers the Emotional Impacts of Childhood Seizures
(Transcript)

Kelly Cervantes: Hi, I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.

Today I'm happy to welcome, Hailey Yoon, to the podcast. Hailey, experienced absent seizures and was diagnosed with epilepsy as a child. After several years of medication, her seizures gradually subsided and eventually stopped completely. Now, a 17-year-old rising high school senior, Hailey, has recently come to recognize the mental health impacts that childhood epilepsy has had on her in the long term.

She's here today to talk about that journey and to share how she hopes to help other children with epilepsy. Hailey, thank you so much for joining us today. To start things off, why don't you share how epilepsy first entered your life?

Hailey Yoon: So when I was in first grade, I started to present symptoms. I had absent seizures, so my mom would notice I would stare off into space a couple of times, and then it became more and more frequent. And so she started to become more concerned and that's when she took me to the hospital and I was diagnosed with epilepsy in first grade, and that's how it entered into my life.

Kelly Cervantes: Now, I'm sure in first grade you don't really know anything about epilepsy, seeing as most adults are not well versed in epilepsy. How was it explained to you what was happening?

Hailey Yoon: For me personally, it was something I tried not to associate with or try to learn more about. So all I knew when I was in first grade was that it was called epilepsy, but I never questioned anything about it or asked anyone about it, just because there was a lot of shame around it for me. So I never really wanted to explore what it meant or what it was in my life. And so I didn't really know much about it at all in first grade.

Kelly Cervantes: You were started on medication. Did the medication help or do you remember there being any side effects?

Hailey Yoon: So for me, with the medications, there was a lot of trouble with that. My family and I, we noticed that either they would have no effect or I'd just have the same amount of seizures and added side effects. Something we noticed was lack of energy, which would contribute to the stress levels that I had. So we had a lot of trouble with the medications and finding one that was right.

Kelly Cervantes: And eventually your seizures just went away on their own. You outgrew it, as it were. How old were you and what did that look like as they were going away?

Hailey Yoon: So for me, it happened between fifth and sixth grade, so right as I was entering middle school, that's when I started to outgrow it. And for me, what we noticed was that there was drastic decrease in how many seizures I was having. I

remember the year between fifth and sixth grade, it was only a few seizures that I had that year, and then it just completely stopped as I entered middle school.

Kelly Cervantes: Which I'm sure was a huge relief to you and your family.

Hailey Yoon: Yes.

Kelly Cervantes: We've talked about absence seizures a bit on this podcast before, but to refresh anyone's memory, can you explain what an absence seizure would look like and what it felt like?

Hailey Yoon: So for me when it comes on, you freeze up and if you were to look at me, I'd just be wide-eyed, staring off into space for around 10 to 20 seconds. And then I would come back and have to reorient myself a little bit. But I do remember it was a little bit unnerving for a couple of my classmates who experienced me just staring sometimes.

There was this moment where I had stared directly at this person and he was unnerved by that. And I think that just contributed a little bit to the shame I felt around having it. I really didn't want anyone around me to know that I had it. But sometimes moments like that I just couldn't help it.

Kelly Cervantes: So you've touched on it a bit, but I have to imagine that shame that you're talking about and wanting to hide it and the embarrassment around that, what was that effect on you socially and academically?

Hailey Yoon: So throughout elementary school, of course, having seizures throughout the day in school can affect you so much academically, just blanking off during lessons in class, it's tough to navigate through school because of it. But also I had this deep fear in me that if my peers somehow knew I had it, or they knew I was different, it would be hard for them to accept me. So I had a lot of trouble around opening up to people and making a lot of friends within that time period when I was in elementary school.

Kelly Cervantes: And now you were one of the fortunate ones to outgrow your childhood epilepsy. But the effects on your life remained. And those, especially during such formative years can have a strong lasting impact on your life. Can you talk to us about the ways that epilepsy is still affecting you and has shaped the person that you've become?

Hailey Yoon: So I've only recently started digging deep into how much it had actually affected me because up until before last year actually, it was just a part of myself I buried and didn't want to associate with. And I realize now how much it had affected so many different areas of my life. As a child, I never really participated in the sports I wanted to participate in, or do a lot of the activities that I wanted to do.

Just because I felt like somehow my epilepsy made me incompetent and my self-esteem was really, really low as a child.

And I think that really developed into my teenage years, and that was how it affected my mental health and everything. There was a lot of anxiety around, "Oh, if people find out, they're going to think I'm different, they're going to ostracize me." There was a lot of anxiety and fear around it.

It really affected me emotionally in so many different ways. I had a school program that I was a part of, it was an independent study program. And I got to work with a mentor and she was a former clinical psychologist and she had pointed out something that I never really realized. But growing up I was always told that my handwriting was really small and she pointed out like, "Oh, you have really small handwriting. I was wondering that might be a reflection of how you felt when you were younger. You felt small and that was just one of the ways it reflected into your life." And I was like, "That's such a small thing in my life." Yet even epilepsy was somehow subconsciously going into the way I was writing and how small it was.

Kelly Cervantes: That is absolutely fascinating the way that showed up in different ways throughout the way that you express yourself. When did this sort of self-identifying and unpacking of the shame that you carried from epilepsy, when did that begin and what kick started that? Because I'm sure that that was a lot to unpack.

Hailey Yoon: So in the last school year, basically I was a part of this program at school. It's the independent study program and essentially what we do is we choose a career that we're potentially interested in and find someone and research a certain topic to mentor us. I had chosen neurology, maybe subconsciously because I wasn't thinking about epilepsy at all, but it had affected my decision to choose neurology.

But I had gotten my mentor, the clinical psychologist, and I started to look into research articles about epilepsy and the stigma around epilepsy. And I was like, "Oh, this is really interesting. Maybe this is what was going on earlier in my life." And my mentor really encouraged me to look into it and everything. And that's how I started digging deep into it. And I started working with my mentor to see how the research was correlating and presenting itself in my life when I was younger.

And that's when I started digging deep into it and now I'm just uncovering everything and going through the journey of that right now.

Kelly Cervantes: I'm sure that is quite overwhelming and emotional at times, but also has to be somewhat freeing. This is a topic that you didn't want to talk about, you didn't want anyone in your family to discuss with you, and now you are on a podcast sharing your journey. That's leaps and bounds from where you were. I wonder,

is this just something that you're now recently talking about your epilepsy or once your seizures stopped, was it something that you ever discussed with your friends?

Hailey Yoon: So once my seizures stopped, no, I didn't discuss it with any of my friends at all. But when I researching into it within the last school year, that's when I started telling the people around me about what was going on in my life back then. And it's been a really recent thing for me telling everyone, "Oh, I had epilepsy when I was younger and this was probably why I was blanking off into space in so many different moments." But everything has been a really recent thing for me.

Brandon: Hi, this is Brandon, from Cure Epilepsy. Have you or a loved one been recently diagnosed with epilepsy? Are you looking for more information about epilepsy and available treatment options? Go to cureepilepsy.org/for-patients to get resources and information about epilepsy. Now back to Seizing Life.

Kelly Cervantes: Now, I understand your work in this school project with the psychologist inspired you to write a letter to other children who are living with epilepsy, and I wonder if that's something you might share with us today.

Hailey Yoon: Yeah, of course. So how it came about though was my mentor, she encouraged me to write a letter to my childhood self or something my childhood self would've wanted to hear. And so based off the idea, I was like, "Oh, maybe I can write a letter that is for all the children living with epilepsy now." And so I can read it for you. It goes;

Dear friend, I have been in your position as well. After my diagnosis of epilepsy, I felt unsure and alone throughout the process. Sometimes I felt ashamed for having epilepsy and other times I felt excluded and different from all my friends. It's normal to feel all these emotions. Having epilepsy isn't always going to be an easy journey.

Something I've learned over the years is that there are so many people willing to support you through your journey. Some people eventually grow out of epilepsy and others have it their entire lives. But remember that there are always people there to guide you. Learn to love all of yourself and don't neglect the part of yourself that makes you special. Shame can make you feel small and invisible, but remember there are so many people out there just like you, feeling the same emotions as you. You are not alone in this. Learn to be proud of who you are. Every part of you is special.

Love.

Your Friend.

Kelly Cervantes: Hailey, that is so beautiful and so meaningful. Especially coming from someone who has experienced it directly, and personally, and has come through it on the

other side. Now, I know that you wrote this letter and it's inspired you to come up with a project idea, and I'd love for you to share that with us now.

Hailey Yoon: So the reason I had actually reached out to Cure Epilepsy in the first place was based off of this letter that I had. I had an idea maybe where adults living with epilepsy or people who have had epilepsy can maybe write letters to children now living with epilepsy. I think one thing for me was when I was younger, I felt very alone throughout the process because I didn't know anyone around me living with epilepsy.

And I think when you have it as a child, you can feel like, "Oh, I'm the only one going through this." It's really hard to navigate that. And so I think having a letter written by someone who has had the experience might be encouraging for a lot of the young children nowadays. And so that was just an idea that I had for a campaign. That's how I reached out to Cure Epilepsy.

Kelly Cervantes: I love that idea and cannot wait to see what we do with this project coming up. Please, everyone stay tuned for more on that. Now looking back, were there any coping mechanisms that helped you? Is there anything that you would say to a parent, any advice that you would offer to a parent who has a child with epilepsy, different tools, techniques that might help their child who is living with epilepsy?

Hailey Yoon: If I were to give advice to any parents or anything, I think it would be to have... no matter how your child may say they're feeling, I remember when I was younger, I would always say, "Oh, I'm fine. I'm fine." It might be a completely different situation. And I would tell them maybe have that hard conversation with your child about how they might really be feeling about everything.

Because for me, it was the whole shame part of it that I felt as a child and I never really talked about it with any of my parents. And of course it's not something I blame any of the adults in my life for just because I think they had thought that if they had appealed to my wishes as a child, that was what would be best for me.

But sometimes having those tough conversations or real conversations, although they might be a little bit uncomfortable, I think they're really important. Especially because when you're a child, everything you do has an effect on your life later. That's what I would say.

Kelly Cervantes: I think that's great advice. And I also wonder, what do you wish your peers had known about epilepsy?

Hailey Yoon: Actually, honestly, when I was younger, nobody really knew what I had or if anyone mentioned epilepsy in any way, nobody around me was really informed about what it was. So what I would tell them, as my peers, would be informing them about what it was in the first place, and how I might experience my

seizures, and how they could support me through that. But also don't see in any way that makes me any different from them or any less capable of anything from them.

Kelly Cervantes: Yeah, I think we could absolutely use more education and more understanding, and through that we would certainly find more empathy. And to cap things off, what is a lasting piece of advice that you would love to give to a young child or a child of any age who is currently facing seizures and epilepsy?

Hailey Yoon: I think something that I would tell them is that there is no need at all to feel any embarrassment or shame around having epilepsy. Just because it's not something within our control, it's not something I ever could have controlled at all. And so looking back now, I'm like, "Why did I ever feel so much shame around this?"

I think it's so easy to get in your head about everything. But something I would tell any child living with epilepsy now is that it's nothing to be shameful about and honestly, I see it as more of a strength to be able to get through something that you're getting through. So I would see it as more of a strength and something that makes you unique and not something at all to hide or carry alone with you.

Kelly Cervantes: Hailey, you are amazing. I am so grateful to you for sharing your journey and your experience with us today. Best of luck. You're heading into your senior year of high school in the fall, is that correct?

Hailey Yoon: Yup.

Kelly Cervantes: Amazing. Well, wishing you so much luck in your future endeavors and have an amazing senior year.

Hailey Yoon: Thank you so much.

Kelly Cervantes: Thank you, Hailey, for raising awareness about the mental health impacts of epilepsy on children and teens. Please keep an eye out later this year for a Cure Epilepsy social media campaign based on Hailey's letter writing idea. Cure Epilepsy was founded 25 years ago by mothers who were desperate to help their children living with epilepsy.

These moms challenged the research community to find cures for epilepsy by better understanding how and why it develops. So much has been learned in those 25 years, and we are closer than ever to finding cures. If you would like to help us achieve our goal of a world without epilepsy, please visit cureepilepsy.org/donate. Cure Epilepsy, inspiring hope and delivering impact. Thank you.

Brandon:

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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's specific health situation.