

## Nikki Ashworth (transcription)

My name is Nikki Ashworth. I'm 40 years old and I have temporal lobe epilepsy on my right side. My earliest memories of having seizures are odd because at the time I was having those seizures, I didn't realize I was having seizures. So my definition of what they were when I was a kid is very different from what I understand it to be as an adult. The way I would describe it as a child was I had these strange occurrences that would happen and maybe anywhere between, I would say 2 to 5 times a year where I just felt incredibly strange that I was disconnected from the world temporarily, but not in a way where I couldn't communicate or I didn't understand what was going on around me, but some type of otherness. I don't know how else to describe it. Just strange feelings, a strange way of perceiving things. I kind of felt like I was in a loop or a feedback loop, which is obviously not a definition I would have used as a kid even. So I don't actually know how like six year old me would have described it because I never talked about it ever. I never spoke out loud about it, really, Aside from maybe saying I felt strange.

My first experience that I can really vividly recall, so I don't know if this was necessarily my first experience, but they, for whatever reason, used to be triggered when I was looking out a living room window on the upper floor of my parent's house. So now I understand that to mean that at the time, for whatever reason, that was a trigger. Sometimes I would go to the window just to see if something would happen or not. And sometimes it did. Usually it didn't. But I do have one memory, and it's the only memory I have of ever trying to explain or share what was going on or how I felt with my parents. I have a memory of saying something to my mother. I don't know exactly what I said, but because I was so young, I probably lacked the vocabulary to say it properly. And I probably, I'm guessing, said something like, "I feel strange" or "I feel funny", like something along those lines. This is the only reason I know for sure the conversation happened is because I remember her response and I remember how disappointed and frustrated I was with the response. And her response was that the feeling I was feeling was nervousness. And she said, "Oh no, you're just nervous." And that really frustrated me because I knew what nervousness was. I had nothing to be nervous about, and I knew that wasn't it. And I don't recall what I said to her in regards to that. But I seem to recall just kind of giving up after that. Like I just recognized, "Oh, she doesn't know what I'm talking about. Okay." And just kind of moving on very quickly from it and not really thinking about it ever again in a way where I wanted to express anything to either of my parents about it.

My seizures as a child did not affect me at all. I was very mentally unbothered by them, which I'm very grateful for. It was just that thing that happened. Sometimes I really didn't think beyond that. It was just these moments of strangeness and they would happen and I would reflect upon them for maybe like five, 6 minutes. And then I go, well, and then I move on with my life. So I am very grateful that I don't have, like any residual upset from that period of my life. Like I never felt neglected or unheard or anything like that. It really wasn't a big deal. When I first got diagnosed, my parents felt a little guilty because they, you know, they said, "Oh, well, we didn't know." And they said, "Well, how could you have known? Right." And I said, "You know, I do recall this one incident, but" and my mom was very apologetic. And I said, "But what would I have said? Like, you wouldn't have understood it. And I'm sure it wasn't making sense. And kids say weird stuff all the time." So I never found it problematic back then. And I don't now. Looking back on my childhood either. My seizures have actually always been the same since I was a child.

How I would describe the way they evolved is not in the way I physically feel when they have a seizure. The mental symptoms, as I would describe them, as well as the physical

things that I feel they involved in volume. So as I would have, I would estimate 2 to 5 a year when I was a kid, give or take. My seizures always manifest themselves the exact same way. They're about a minute long and they always start out the same way. Nine times out of ten, I'm outside. Being outside is my trigger. Very rarely do they happen in doors. So more often than not, I'm outside. These symptoms happen all at once. So you have to work with me here because they're very hard to describe to somebody who's never had them before. It's like trying to ask somebody, "What does a colour sound like?" You know, unless you have I guess that's called synesthesia, I think that's called it's really difficult. So just go with me on this because it doesn't sound probable or possible.

Number one, I immediately get a sense of over familiarity of things. I would describe it beyond casual déjà vu because I have what I call regular déjà vu to everyone has those moments. But this is a profound understanding that everything you're experiencing in the present as it happens, millisecond by millisecond has happened before and before and before. So it's this very weird kind of spooky, supernatural idea. Not that you can't anticipate what will happen next, but it's this deep spiritual knowing, for lack of a better word, that what you're experiencing has absolutely 100% happened before. And this harkens back to the feedback loop I mentioned, because it's almost like a cyclical thing, moment to moment. You're getting these messages from your brain saying, yes, this happened before exactly like it's happened before in that car that drove by, that was blue and it made that all noise. Yes, that happened before the last time and so on and so on and so on simultaneously. At the same time, I get physical symptoms. So it starts with a warming sensation in my lower abdomen. And this hits me just at that same time. I get that profound knowing concept. And it's a radiating heat. Not in a way where it's burning or uncomfortable the way heartburn would be. It's just unusual. And this radiating sensation travels up my abdomen very, very slowly. And as it's working its way up my torso, I start feeling nausea. It makes me cough. I've never actually thrown up ever in the entire history of my life have I thrown up from it. But sometimes I need to cough a couple of times or clear my throat. So that's happening at the same time. The rising sensation of this heat almost makes me feel like I'm being taken up a roller coaster at the same time. So I'm usually standing when I have a seizure. So it's almost like your body is physically being elevated. I don't feel like I'm floating off the ground. I feel more so like I'm going up a roller coaster anticipating this drop as the heat travels up my body. By the time it gets to about my shoulders, that's when I know the drop is going to happen. I refer to this concept as the hourglass, because I can actually calculate how many seconds left I have in the seizure based on where the heat is in my body. If it's at like chest level. I know I have about 20 seconds left, so that can be very helpful to you because it can help me ride it out because I know. Okay, only 20 more seconds of this. So then when it reaches my shoulders, that's the drop. So that's when you physically feel that you're being dropped or you're going down a roller coaster. So it's almost the sensation of falling. So it's a rise, I guess. And then you drop down. And by the time the drop down ends, it's over. It's completely over.

The sensations I feel, the nausea is gone. It can leave me fatigued, not confused, just tired sometimes, especially if I have several in a row. Another symptom I experience, which I find really bizarre, is a sense of dread. And I don't say fear because to me a concept of fear and dread are very different from each other. I'm not afraid. I feel like something very bad is going to happen, but it never does. And because it never does. Even though I experienced it so deeply. I have that other part of myself that I'm still in control of that can tell that part of me saying something very bad is going to happen, saying, No, I won't shut up. You've done this before. How many times? Nothing bad is going to something that's going to. No, it's not going to happen. So you have this strange duality because you're not in control of certain aspects of what you're experiencing, but you can also consciously fight

with it at the same time. It feels like the world cracks open for about a minute, and you're the only one who notices. And then it just goes up. And then it goes back as if it never happens. Because the whole world, like your whole perception of everything, just goes loop. And then it just as easily flips back as if it didn't happen at all.

People would not notice him having a seizure at all. I've had them my entire life, had seizures at work. I've had seizures too. And from getting coffee at work with co-workers, I've had seizures, crossing streets with my boyfriends, talking to friends. There really are no symptoms with me. And I think that's partly what I think. I know that's why I wasn't diagnosed until I was 30. I think I was 37 when I was diagnosed because there's no towels and because I'm completely conscious and able to speak freely without any strangeness in my cadence. No stuttering. I'm not, you know, necessarily tugging on clothing or fabric or doing other things that can be signs of other types of focal seizures. I'm completely with it. And I'm also a master of hiding it. So I think maybe I do a better job than most people because I'm just so good at hiding it. I accept the differences now because I understand what's happening. I can freely say to somebody, if I'm with them, I'm having a seizure right now, and usually they turn to me. Yeah. Oh yeah. And they're shocked, you know? And sometimes people will look for things like they'll let me look at your eyes and fine, you know. Do you feel weird? Yeah. Are you okay? Yeah, I'm okay. You know, so there really are no symptoms with me. I think that is definitely unusual. I reflect on this a lot. I think it puts me in a very privileged position as well as far as people with epilepsy go. I am fully conscious. I'm aware. I don't drive, but I could drive if I had a clear sense. And I don't receive the same type of discrimination from people because when I'm having a seizure, only I know, and I can choose to share that with somebody or not. So, within the spectrum of epilepsy, I believe that I am with the luckiest group. That's how I personally look at it. I just feel very fortunate that I don't have to deal with a lot of the other taboos and struggles that other people with epilepsy face on a daily basis.

My understanding is that lack of symptoms is indicative of focal aware seizures. If you have those exclusively, which I do. Most people that at least I've spoken to with focal aware seizures also have different types of seizures. I've never met anyone who exclusively has focal aware seizures. Aside from one lady. So, it was really fascinating talking to her. I think that her experience even experiencing them was a lot more upsetting to her than it was for me mentally. So again, that can make a big difference in, you know, your point of view on having them. What prompted me to first seek diagnosis was having many more seizures than I used to. It got to the point where I was having about 3 to 4 a day, and one day I'd had quite a few. I'd been with my boyfriend, and I even had a seizure on my way to his house. And when I got there, I felt like I just had to say something about it. And I said, just does that ever happen to you? And he just looked at me and said, I think you need to speak to a doctor. I found that comical because it honestly never occurred to me it was medical. Which is embarrassing. Upon reflection, I have no idea why it didn't occur to me it was a medical thing. I always, throughout my adult life, tried to think of it more in terms of I was experiencing someone else's death accidentally because perhaps there was some sort of time space continuum, wormhole scientific thing. I didn't know that was happening that I was particularly sensitive to, which is a lot more complicated than something's wrong with your brain. So, I don't know why I went there, but that was my thinking for the longest time was that I was experiencing things that for whatever reason, I was not meant to, for whatever scientific reason, beyond my own head, which is the most obvious place to think of. So, when he said that to me, I actually laughed and I was being really facetious and I said, "Oh yeah, what am I going to do? Google déjà vu, but medical?"

And so, I actually typed in 'déjà vu medical' in Google on my phone. And the very first thing that popped up was an epilepsy website from the UK. I looked at it and I laughed again, and I went, "Oh, you know, f off." Ridiculous like that. No, I don't have epilepsy, because as far as I was concerned, the only type of epilepsy I knew was what I now know are called tonic-clonic seizures. But I knew them as grand mal. So in my head, I was like, "Well, that's obviously wrong. You know, I'm not having grand mal seizures. How utterly ridiculous." Didn't think two thoughts about it until a couple of weeks later. I saw I was having seizures again that whole time. Still hadn't done anything about it. And then one day when I was at work on my break, I got up the nerve to look it up again. And I went to that same British epilepsy website, and I read about what they referred to as focal aware epilepsy. They had a list of symptoms. I was reading about myself and I knew immediately. Deep, deep, deep in my gut it was right.

I think in hindsight now, I understand that it probably in many ways shaped who I am as a person in general as a whole. I was very calm. I've always been weirdly calm, full of wonder and excitement almost about this, because I've learned about myself. I've learned about my brain. I've learned things about my brain. I've learned things about my memory that most people never get the chance to experience. Never even the memory testing alone that I found very difficult. And I was frustrated at the time to do it. But just getting that feedback, like actually learning about how my mind remembers things. Fascinating. Absolutely fascinating. And I've been continuously fascinated, which I know again is unusual, but I tend to be a pretty positive person in general. And this has just been so damn wild. When I talk about it. I feel like I'm talking about a movie I saw. I just find it so interesting and to really know myself that way so intimately. And because I had it my whole way and all it's done is allowed me to learn about me. That's it. I don't look at it as an enemy.