

**Seizing Life, episode 90**  
**Monitoring Mental Health in Kids with Epilepsy**  
**Guest: Madison Berl**

- Kelly Cervantes: 00:00 Hi, I'm Kelly Cervantes and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy.
- Kelly Cervantes: 00:18 Today, I'm happy to welcome Madison Berl to the podcast. Madison is a pediatric neuropsychologist specializing in epilepsy and seizures at Children's National Hospital in Washington, DC. She's here to talk about the psychological and emotional issues that can arise in children and adolescents with epilepsy, how to recognize the signs, where to turn and what to expect from treatment options.
- Kelly Cervantes: 00:43 Hi, Madison. Thank you so much for joining us today. To start out, why don't you tell us what exactly a pediatric neuropsychologist does? What kind of patients you see, because this particular specialty is new to me.
- Madison Berl: 01:06 Yeah, absolutely and you're not alone. Even my colleagues I worked with for many years still get us confused. Pediatric meaning I work with children, so that's pretty straightforward. Neuropsychologist, my training is as a typical psychologist. I have my PhD in clinical psychology. I learned to do therapy, assessment, typical psychologist things. The neuropsychologist comes into play because like an MD will go to medical school and get general medical training, then they start to specialize, a neuropsychologist also specializes in post doc work and that is focused on assessment and really learning those brain behavior relationships. That's my specialty. A little different than a psychologist because I tend not to do as much therapy anymore. I do more of the assessment and really focusing on neuroanatomy and understanding how the brain works to get all those behaviors that everybody shows.
- Kelly Cervantes: 02:17 Got it. What kind of patients do you see?
- Madison Berl: 02:23 Any child who has some sort of learning problem, emotional problem, social problem may come to see me. Sometimes they may go see one of my colleagues. To go off a little bit more what you said, I'm a little different than a speech language pathologist who'd focus on language and speech. Where I'm going to look at intelligence, memory, attention, a range of abilities. Sometimes a child will go somewhere else first, because they're having attention problem or a language problem or a social problem. But they'll come to us to really understand the full picture because it's not so clear if it's just one thing, it may be a bunch of things. Same with a neurologist. They may also refer to us because there's learning or social or

emotional problems accompanying a disorder like epilepsy and they want to see what do we have to say about the child's functioning that may be related to that disorder.

- Kelly Cervantes: 03:34 Got it. Do most of your patients come to you with a doctor referral or is it sometimes parent, guardian advocate, super parents reaching out and wanting these evaluations?
- Madison Berl: 03:53 Yeah, we do work in an academic medical center, I work at Children's Hospital in DC so most of my referrals are coming straight from the neurologist working with the epilepsy team. And same with colleagues of mine who work with oncologists, cardiologists, those specialties. However, depending on where you are, this is DC, there's a lot of savvy teachers and parents and they know that we can also be helpful to them. Even if you don't have a medical disorder, looking at the kinds of problems, like attention, learning in general, again, social problems, they'll come to us to answer those questions of this child's not thriving in some way. Can you help us understand why?
- Kelly Cervantes: 04:42 Now we've spoken a lot on this podcast about the physical, mental health implications that epilepsy can have on adult patients. I'm wondering what are some of those common effects that you see in the pediatric epilepsy population? What statistics do we have?
- Madison Berl: 05:07 Yeah, we really do see that those same problems that you see in adulthood probably started when they were younger if they had their epilepsy younger. In particular, we know that epilepsy biggest incidences of onset is in childhood, under age five. Those kids, especially the genetic epilepsies, you're going to see a lot of those issues emerge quickly because they're not walking, they're not talking, those kinds of more severe difficulties can show up real quick. Then other things like attention problems, language problems, social problems, we may not recognize those as beyond maybe just having a chronic medical condition as a problem until we expect those kids to start having friends and needing to pay attention more. So we see them emerge at all different ages, but they can be very early.
- Kelly Cervantes: 06:10 What studies have been done? What statistics do we have access to?
- Madison Berl: 06:16 Yeah, one of the first questions we always ask is how common is this? Even any parent gets a diagnosis of epilepsy like, "What are my chances that this is going to be something else I have to deal with in addition to these seizures?" That's the studies that

have been done most, is just really identifying the problems and those problems we have are similar to adults. If you take everybody with epilepsy, about a third of children with epilepsy have some sort of comorbidity and that's the range. It can be intellectual impairment, it can be ADHD, it can be autism, it could be language problems, motor problems. That's probably in general, if you take them all together. So the good news is most kids do really well.

Madison Berl: 07:08 Having said that, there are other factors in the person's epilepsy or other certain types of epilepsies, I mentioned the genetic epilepsies already, they're going to have a higher incidence where it's more common. You take something like tuberous sclerosis complex, well, that's a little bit higher than those kids have autism. That's closer to 50% of kids with TSC may have autism. So it depends on other risk factors that go along with their type of epilepsy because we do know epilepsy is pretty broad in what it can present as. So those statistics will change what that type of epilepsy that you have.

Kelly Cervantes: 07:50 Now, talk about different learning disabilities, ADHD, these different comorbidities that are more likely to impact these pediatric patients with epilepsy. What about anxiety and depression?

Madison Berl: 08:06 Yeah, that's definitely part of in my world of the scope of comorbidities. And anxiety and depression, depression is the most common in adults. I think it's a little bit different for kids. I think it presents a little bit more like anxiety when they're littler and then that depression may set in a little bit later as they think about the consequences of their epilepsy. Earlier on, there's a lot more fear. Sometimes that's the fear of having a seizure. Sometimes it's the fear of what other peers may think. It's the fear of being out of control if they were to have a seizure and not know what's going to happen. That anxiety and depression are definitely part of it. There's also some shared brain regions that those same areas that manage our anxiety and depression are also one of the most epileptic areas in the brain, and that's the temporal lobe.

Kelly Cervantes: 09:07 You mentioned some of the different ways that anxiety or depression may show in children. What other signs should parents be on the lookout for when trying to determine if they need to take their child to be evaluated?

Madison Berl: 09:25 Yeah, that's a good question because I do think some families and some doctors hesitate and say, "This is maybe just the adjustment to having seizures. Maybe it's just the stress of that

and is it really something that we need to address?" I would say you are going to do the same thing as if your child doesn't have epilepsy. If you see something that's impacting their functioning and you're worried about them, you need to go have it evaluated. Those signs can be changes in their behavior, not being out there socially as much as you would expect, changes in sleep, eating. Just like all of us, if we're depressed or anxious, we have those kinds of changes.

- Madison Berl: 10:19 The other thing that kids do a little bit differently than adults is some regression. Maybe they were fine at night and dry and then they start wetting the bed again. Or they're a little bit more clingy, they won't go out anymore. They used to go fine into the park or over to a friend's house, but they want to stay home and they want to be close to you and they have a hard time separating from parents. Those are some of the signs that things might be changing for them or they're not doing as well.
- Brandon: 10:57 Hi, this is Brandon from Cure Epilepsy. Since 1998, Cure Epilepsy has raised over \$85 million dollars to fund more than 270 epilepsy research projects in 17 countries. Learn what you can do to support epilepsy research by going to [cureepilepsy.org](http://cureepilepsy.org). Now, back to Seizing Life.
- Kelly Cervantes: 11:17 Just thinking of the doctors that a child with epilepsy is going to see regularly, clearly their neurologist, their epileptologist. Is this something that a parent should expect their epileptologist to be screening for and discussing with them?
- Madison Berl: 11:34 Yeah, it's actually part of the American Academy of Neurology quality measures for taking care of epilepsy. It's very much in the literature and guidelines for best practices. Having said that, I give the neurologists a little bit of grace here where they're trying to deal with a lot of things and they're trying to address a lot of things. Especially at the beginning, when it's your first visit, their main job is to stop seizures and to address the medications to do that. So you may not hear about it at the first visit. However, it is something that I think over time and probably on an annual basis, again, people see their neurologists at different rates so it's hard to say. It should be something that is discussed. There is literature to show that the neurologists are aware that parents want to know about this and are concerned. So the neurologists are having that conversation a lot more often.
- Kelly Cervantes: 12:38 Well, that is good to know. Also, I suppose for the parents out there, if your doctor, if your epileptologist, isn't discussing the psychological impacts ask, right?

Madison Berl: 12:51 Yeah, absolutely. I think the message that epilepsy is not just the seizures, it's more than that, is really a message that is loud and clear. I do think for the most part, unless they've been under a rock, most neurologists are understanding that it's beyond just the seizures. So asking about learning problems, behavior problems, emotional problems is more common we would hope. But yes, as parents, you want to do the same thing, it's a mental health check. You don't have to just talk to your neurologist. You can talk to your pediatrician. And if it's a concern you can talk to anyone who has that experience of knowing kids, a teacher, anything like that.

Kelly Cervantes: 13:34 Are there certain things that a parent can look out for to try and determine if it is a cause of the epilepsy or if it's the cause of a medication? Because I think there's probably some fear and we'll get to it in a minute of adding a new medication to try and treat something if it's the result of a medication that the child is already taking.

Madison Berl: 13:58 Yeah, I think again, just as parents and with a new diagnosis, you need to get to some stability. You don't know what's what until you get a little bit of time and a little bit of understanding. I completely agree the focus is on the seizures, taking those medications. I do think as much of a pain it can be sometimes, keeping careful track of when a seizure medication was started. A little bit different than when it's a situational or a family history, genetic loading of attention problems or social problems. A medication effect is pretty quick, it's pretty acute so you're going to have a quick behavioral change. And if you really can't explain that by some significant event, then it could be a medication. That's one factor. If it's a little bit more of a gradual and the same, but if you have a quick change and you just had a medication change, that's more likely a medication effect.

Kelly Cervantes: 15:07 When do you suggest that a parent reach out to a neuropsychologist and how frequently do they meet with them?

Madison Berl: 15:19 Yeah, that's a good question. Again, it depends on your epilepsy. Most seizures are treated successfully with medications and so that's good. There's other seizure types that are more of a progressive, long term, you know you're going to be dealing with it for a while. Sometimes you know that at the beginning, sometimes you don't. If that's the case, a good time to see a neuropsychologist is as early as possible so you can get a baseline. For example, you know your kind of epilepsy may be harder to treat or there really is no cure. You know the seizures

are going to be a while, getting a good baseline to know where your child is at is important. We always recommend that when you know you're going to have something big like a surgery or some other device implanted or things like that. You want to get that baseline before you make all these changes.

- Madison Berl: 16:23 You can also do that with medications. Sometimes we'll just do a quick screen before starting medications, just to see where a child is at and then we'll follow up a month or two later after that. Most people don't get to see a neuropsychologist every year. They'll tend to wait until something big changes and that's for good reason. It's time intensive, it's a day long appointment and you may not need it. And the waits can be long, depending on where you are. There may not be a problem for a while, so a lot of children do really well. Early on language is okay, motor is okay. They start school, they learn to read okay. It's not until maybe they get to third grade, or fourth grade, or fifth grade when the demands go up on them. That could be social demands, that could be attentional demands and that's when you see the problems. Coming in for a neuropsychology evaluation at that point may be the best point because that's when you're having problems and that's when you need to have the recommendations and understand what's going on.
- Kelly Cervantes: 17:37 What should be expected in terms of treatment for one of these psychological comorbidities?
- Madison Berl: 17:45 The good news is all the treatments that we know work in children without epilepsy, work for children with epilepsy. That includes medication, which is again, something that parents are really hesitant to do. I really get that when their child is on other medications. But the initial thought, and I still have some neurologists that will say this that, "Oh, if I give them a stimulant," which is the drug that is the first line treatment for ADHD, "it's going to lower their seizure threshold and they'll have an increased chance of seizures." There's so much evidence to show that that is not the case and for years. That's a myth that's out there. You need to treat the ADHD, the anxiety, the depression, and you don't want to add to the problem by having an untreated mental health disorder.
- Kelly Cervantes: 18:42 That is incredibly good to know that those medications are safe and that it's not going to affect the seizures. Ideally insurance covers these sorts of evaluations, but it doesn't always.
- Madison Berl: 18:59 It doesn't.
- Kelly Cervantes: 19:00 What do you recommend in those situations?

- Madison Berl: 19:04 Depending on what the issue is, if it's a learning problem and your child is struggling in school, everybody, no matter where they are, has the right to ask for an evaluation from the school. They may do it a little differently than what I do, but they're at least going to get those basics. IQ scores, what is their thinking skills and their academics, how are they doing? Usually that's what we care about as parents. If they're reading, if they're doing their math, those kinds of things. A school is mandated to do that by law and it's free. Again, there's sometimes waits and things like that, but that is a very good place to start if you can't get it covered by insurance. There's other things you could do. I live in an area where there's a lot of universities and sometimes they'll have training programs that can give you an evaluation for free or on a sliding scale, by a trainee. Those are some out of the box options, but I would definitely start with school first.
- Madison Berl: 20:07 Then the other thing that we have, I know all the parents listening get their pit bull skills going and they got to go after and appeal those things. You can ask us, I have tons of templates for neurologists, for parents to say, "These are the reasons why this needs to be seen by a neuropsychologist." Because things like memory, that's not a skill that the school typically evaluates, but if you have something like temporal lobe epilepsy, it's a very specific skill in children that doesn't even always show up as a problem for other disorders. But it's very specific to epilepsy and you do want to get their memory checked out. They could have a true memory problem as opposed to an attention problem or something like that.
- Kelly Cervantes: 21:00 Talking a lot about young children, getting them to see a neuropsychologist, getting them in for an assessment or for mental health therapy, a younger child is easier to convince of these things or just brute parent force. Teenagers can certainly be a little trickier and their issues are just as present and potentially even affect them in a greater fashion. What do you suggest tips and tricks for parents who are trying to convince their teenager that they need this psychological help?
- Madison Berl: 21:44 Yeah, teenagers, just normal development, they want to separate. That's what they're supposed to be doing. They want their independence, they want to stretch their arms and say, "I don't need you mom and dad and I want to be with my friends." Epilepsy puts a little wet blanket on that because sometimes they need some extra supervision. They don't have independence if they can't drive, if it's something like that. As parents, being worried that my child is going to have a seizure is something, especially if it's a new onset, I'm going to be watching them a little bit more like a hawk just at the point

where they don't want to be watched. Having that understanding of each other, what are the things that can be done that help both sides? That's the place that I always start, is what do you want, what does the teen want? And where are those shared things that you can agree on?

Madison Berl: 22:52 It's not okay if I don't know where you are. I have actually helped many a teen get a smartphone, because guess what? You can track your teen, but that's the agreement. If you get a smartphone, you need to have the tracker on. You can find ways that both sides are going to be happy, but engaging both sides in order to come up with a plan, because everyone needs to agree. As a parent, there's a red line. You have to be safe and I have to know that you're safe. You have to be with someone that knows what potentially could happen, what your seizure looks like, where your rescue meds are, all of those kinds of things. That teen needs to go through a few steps in order to allow the parent to feel safe. Having a friend know that they have seizures, sometimes that's the first step. The teenager doesn't want to disclose to anybody. They're not going to be able to do what they want to do unless they disclose. There's a few processes, but the most important thing is doing it together and finding that common ground of agreement.

Kelly Cervantes: 24:07 I'm guessing that a neuropsychologist can help negotiate that, arbitrate these agreements. Mediate so that those resolutions can be decided upon would be exponentially helpful.

Madison Berl: 24:28 We'll do a bunch of testing and give a profile of strengths and weaknesses and the feedback, we give recommendations. During that point, we're hopefully giving both the parents and the child the rationale for why we're saying we need to do what we do. Or why we're suggesting what we're suggesting. The social problems can come for a lot of reasons, there's some kids that just don't get the social cues. That's one issue. There's other kids that have the stigma attached and are afraid to disclose what they are going through with their peers and don't know how to talk about it.

Madison Berl: 25:14 Depending on each child, we may go through that and we may have to have some other follow up sessions. That can be with a neuropsychologist, that could be with a regular psychologist, as well. A therapist that you might see more often, depending on again, how big those issues are. Medicines are one thing for dealing with anxiety, depression, stress and stigma, family dynamics, all those kinds of things. But going to a therapist, a social worker, a school counselor to come up with coping strategies and doing that talk therapy to work things out is also



really important and sometimes more effective than the medicines alone.

- Kelly Cervantes: 26:00 We had a guest on the show just a few weeks ago, a teen who discussed how she went to an epilepsy group therapy session and how much she enjoyed that. Is that something that you recommend as well?
- Madison Berl: 26:17 Yeah, and definitely for teens. Again, back at this belonging is a key thing for teens. Finding their peeps and their community that they can say, "Okay, this is where I belong," whatever that is. For some it is this shared experience. We have some of those groups, not always specific to epilepsy, but having a chronic medical condition and understanding what that's like for anybody that has to deal with that for school, for friends, for relationships. I think that can be really helpful so they don't feel so alone.
- Kelly Cervantes: 26:57 What do you suggest for the younger child who is perhaps a little more apprehensive or nervous about getting evaluation or getting that psychological assistance?
- Madison Berl: 27:11 Yeah, I think sometimes that is, not to blame the parents, but I'm going to have the parents do a little check on themselves on this one. Is it them, or is it you and your nerves? Or is it you and your preconceived ideas about this? Because a lot of times a younger child's going to take the cue from their parents about how this is. Going to a psychologist is just like checking your heart and your growth. You need a mental brain check. Going to a mental health professional is the same as going to a pediatrician where you're just checking your brain, making sure that you're on track and developing in the way that you would expect. If there's any issues, any concerns, that you're able to talk, ask questions, is this normal, all the things that you would do. A parent that portrays that same kind of attitude, a child will usually pick up on that as well. Explaining it at that level of just a brain check, see how you're thinking and feeling.
- Kelly Cervantes: 28:22 Yeah, it sounds like this neuropsychology piece is refreshing because it's solutions oriented therapy. That there are treatments, that there is proof positive here of things that work and that can help. I hope that this information that you've so graciously provided for our families listening can really help shine a light forward and let them know that there is this specialty. That there is this help out there that can help with those behavioral and psychological comorbidities that so frequently come along with epilepsy. Madison, thank you so much for sharing your knowledge and expertise with us today.

Madison Berl:	29:12	Absolutely, it's my pleasure. Thank you.
Kelly Cervantes:	29:18	Thank you Madison, for sharing your insights and expertise on mental health in children and teens with epilepsy.
Kelly Cervantes:	29:25	For more than 20 years, Cure Epilepsy has been dedicated to funding patient focused research to find a cure for epilepsy. You can help us in our mission by visiting <a href="http://cureepilepsy.org/donate">cureepilepsy.org/donate</a> . Through research, there is hope. Thank you.
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