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The Seizure Reporting Gap: Improving Epilepsy Care Through Patient–Physician Collaboration

[00:00:00] **Intro:** Welcome to Amplifying the Patient Journey, a series in which we speak with both providers and patients about the clinical journey with a neurologic condition and what recent advances mean for patients, their providers, and caregivers. In this episode, Landis Weidner, epilepsy advocate and host of the What the Eff podcast, and Danielle Becker, MD, division director of epilepsy at The Ohio State University Wexner Medical Center, in Columbus, Ohio, discuss the importance of open communication and shared decision-making in epilepsy care.

[00:00:34] **Billy Irving:** Okay. Thank you so much for joining us today, Dr. Becker and Landis, for this episode of Amplifying the Patient Journey. Landis, could you please introduce yourself briefly if you if you don't mind?

[00:00:42] **Landis Weidner:** Yeah. My name is Landis Weidner. I am the host of What the EF Podcast, which is an epilepsy podcast for adulting with epilepsy.

[00:00:51] Just bringing conversations about difficult topics and couching them in laughter and casualness just to make it a little bit easier to talk about all [00:01:00] that stuff. So yeah. And that's, And I've been doing that work on, starting year five in January.

[00:01:04] ...

[00:01:04] **Billy Irving:** awesome. Thank you so much. And Dr. Becker, could you please introduce yourself?

[00:01:07] **Dr. Danielle Becker:** Yeah. Hi h- hi. My name is Dr. Danielle Becker. I am an adult epilepsy provider, and I am currently the division director of epilepsy at The Ohio State University Wexner Medical Center. And I'm very excited to join Landis today and have this conversation with you.

[00:01:21] ...

[00:01:21] **Billy Irving:** awesome. Thank you both so much for joining us....

[00:01:23] ...

[00:01:23] Um, so, to start with uh, Landis, you've been living with epilepsy for almost a decade. Could you take us back to your diagnosis and tell us what living with epilepsy looks like for you today, including how you came to advocacy and hosting your podcast, What the EF?

[00:01:37] **Landis Weidner:** Yeah. So I was 32, and I needed a craniotomy to remove a brain tumor and also radiation after the brain surgery.

[00:01:45] And I was about two weeks into radiation treatment when I started having epileptic seizures. So that was a lot to handle all at once to say the least. And I was also living alone and single at the time so it was a- an isolating [00:02:00] experience. And there was just a big difference I noticed between my journey with the, the brain tumor where it was like, we're surgery, radiation, here's clear path to treatment.

[00:02:11] And then with the epileptic seizures, it was like we're gonna try this, and then we're gonna try this. And then, you also need to be very careful about sleep and stress and all these things. And I, this is embarrassing for me because I have close family members with epilepsy, and I did not understand how much of epilepsy goes beyond seizures until I was diagnosed myself.

[00:02:37] Just establishing a daily routine to help mitigate triggers managing medications just getting all of that down. And so it got me


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into this place where I was just looking for someone else going through my experience. And I felt like I couldn't find anyone, and just feeling really alone.

[00:02:56] And once I started to find other people, I was like, "You know what? We [00:03:00] need to let other people know we're out here." And so it started with writing because that's my first love and passion. And it was awesome 'cause I got some pretty good bylines, like in NBC, in The Independent, in Wired, and and they were about epilepsy, and I loved that.

[00:03:13] But I also realized that it just wasn't reaching the biggest audience. And also reading and comprehension can be difficult for someone with epilepsy, whether it's, because they've had a seizure or you know, medication side effects or whatever it might be. And so I was like what's out there that's free and accessible and audio?

[00:03:33] Oh, we've got podcasts." There's already this platform out there for me to try it. So I Was like, let's just do it. Let's just try to, show people that other people are out there living with epilepsy and that who have jobs and who are also fighting the same battles and dealing with, just not only seizures, but just managing adult living."

[00:03:57] Whether that's workplace stigma [00:04:00] or whether that's dating or any of those things that everyone kind of deals with, but with epilepsy there's just a different layer to it. And just because it's my favorite coping mechanism, I throw in some laughter. And I think that's really what makes the podcast more approachable is that there...

[00:04:16] because listening to a conversation about your chronic illness can be difficult, but I like the fact, and I think my audience likes the fact, that there's, you're always gonna be laughing while you listen. And so that's, that's really why I built it out, was just as a way to reach people. that was just the kind of most accessible way.

[00:04:35] 'Cause podcasts are everywhere, and they're free. Or at least this one is. And and so yeah. And then it just took off. Within the first nine months it was in the top 10% of podcasts globally, which just shocked me. And I was like, "Okay, so we do need this." People are craving this sort of connection and this needing to feel seen, and maybe also have a little bit of a chuckle along the way.

[00:04:56] So yeah, that's, and that's how I got here.

[00:04:58] **Billy Irving:** . Yeah, we definitely agree that podcasts [00:05:00] are a great way to be- to reach people ....

[00:05:01] **Landis Weidner:** ...I thought you might.

[00:05:04] **Billy Irving:** So y- you've mentioned that you didn't tell doctors about every seizure you would experience. What was going through your mind to make you not wanna tell your doctors about y- the seizures?

[00:05:12] Did it come down to believing that seizure freedom might not be something that was possible to you? Or were there concern about medications, or driving, and work, and independence? Or what specifically were you thinking about,

[00:05:21] **Landis Weidner:** Yeah, that's a great question 'cause it sounds crazy when you're like, "Why didn't you tell your doctor about all your seizures?"

[00:05:27] And it was really, there's, there wasn't one reason in particular. I could probably point it to a few where sometimes for the smaller seizures where they're like w- were called auras or sometimes in the epilepsy community, people with epilepsy, we call them baby seizures.

[00:05:39] We don't Think they're a big deal. And so I, that's where I was at. That's the camp I was in. I didn't, I honestly didn't know it was something to be reported. And then I learned I was not the only one. SK Life Science put out this survey that showed that three of four, four patients do not consistently report their seizures to their healthcare [00:06:00] providers.

[00:06:00] Which for me was really validating because I needed to know that I wasn't the only one doing this before I could feel comfortable sharing it with my doctor, if that makes sense, because I felt very dumb when I realized I should be reporting this stuff. And then there was, yeah, the another reason too was, like, yeah oh this medication is working f- and or it has maybe a little mood booster in it or something, and maybe I don't wanna mess with this medication. And th- there's a ton of reasons why people don't report it. And I think it just feels, I don't know. It's just something that once I learned that I wasn't the only one not reporting it, for some reason it just helped i- embolden me to be like, "Oh, okay, I'm not the only person who does this.

[00:06:36] Now we know that. Now we can get over this hurdle." But I also know I've talked to so many people who, they feel like they're rushed in their appointments. I'm very fortunate where my doctor has never made me feel that way. And then a lot of people are afraid of, losing independence through driving especially.

[00:06:51] And I think independence is a big one just because epilepsy just chips away at your independence immediately with


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diagnosis almost. For me, I live in Chicago I s- [00:07:00] I didn't even have a car when I was diagnosed with epilepsy. So I think, I think that for me, like, minimizing the importance of my seizures was a big part of it.

[00:07:08] But once I started talking to- to my doctor about it, and I was like, "Hey, listen I didn't know I... is this something that..." She was like, " "Yeah, you should be talking about it." And I'm like, "I'm so sorry. I just didn't..." And we had this really wonderful conversation where she was like...

[00:07:22] 'Cause she felt bad that I didn't know that I should be talking about it, and she was like I'm so sorry I didn't communicate that with you," and I was like, "You might have, and I might have forgotten," so it's just like this where... And it really helped grow our partnership and our relationship as doctor and patient once I was able to come forward and just be like, "Listen, I have...

[00:07:40] I don't think I've been telling you everything. Is this stuff I should be telling you?" And she was like, "Oh, yeah, 100%."

[00:07:45] **Billy Irving:** Yeah. Thank you so much. And moving over to Dr. Becker does What Landis describing match what you're seeing in your practice? We've seen research suggesting that clinicians assume they're hearing more...

[00:07:50] Sorry. We've seen research su- suggesting clinicians assume they are hearing about more seizures than patients are actually reporting. Do you have any idea why this gap might exist and how... What, what factors lead into that?

[00:07:59] **Dr. Danielle Becker:** Yeah, thank you very much. Landis's story [00:08:00] is very common. I think sometimes it's that not everyone realize what a

[00:08:00] Sorry. I think that sometimes not everyone realizes what a seizure is. And so these auras that we talk about, these baby seizures, as Landis put it so well they're not what on TV. They're not what you think of when you think of seizure. Sometimes they're just a deja vu or a rising sensation or this intense fear or feeling of doom, but then it goes away.

[00:08:19] And so I think part of it is the education, that some people might not realize it's a seizure. And then the other part of it is a lot of what Landis had said of, "You know what? Right now is good enough," or, "I just got into this routine. I don't want to rock the boat," or, " I don't want to lose my independence.

[00:08:34] I don't want to be told I can't work or can't drive." Now, as far as why providers may think that they are hearing about all the seizures, I think that sometimes we don't always understand what our patients are going through or may or honestly just may not be able to relate fully because we ourselves have never experienced it.

[00:08:56] And so we might think, " "Oh they're coming to me for treating their [00:09:00] seizures. Of course, they're gonna tell me all their seizures because then I'll change management," not realizing that of course they'll tell me all their seizures because then I'll change management is actually a deterrent.

[00:09:10] They don't want to change management because they finally feel better than maybe they felt before. And, as, as Landis said as well, this independence. Epilepsy takes away from so much. Sorry. And like what Landis said, this, this independence. Epilepsy takes away so much from people living with epilepsy.

[00:09:20] Now it's going to relate to decisions that are out of their control. So if they say one thing, a whole set, a whole cascade of events might start to happen, and they may feel like they're losing even more independence. And then the last thing I want to say is that a lot of times patients may not know that they've had a seizure.

[00:09:37] We know that seizures can impair memory, not only during the seizure but after the seizure, just in between seizures. And there's a study in the epilepsy monitoring unit saying that when patients were in the epilepsy monitoring unit and being monitored, about 50% of them, the patients didn't even know they had.

[00:09:54] And especially if you have nighttime events or nocturnal events, a lot of times patients are unsure, [00:10:00] and they may wake up the next morning and say, "Oh, I ... I feel weird. I'm not sure." So I think there are a multitude of reasons why someone may not tell their doctor or may not even know to tell their provider.

[00:10:10] **Billy Irving:** And so what's exactly at, at stake here when a neurologist doesn't have the full picture of how many seizures a patient is experiencing? What's missing and why is that so crucial?

[00:10:18] **Dr. Danielle Becker:** So it's hard because right now the way epilepsy is we live in this black box. When a patient comes in and says, "I've had seizures," we say, "Okay, let's change your management 'cause your drugs aren't working."

[00:10:28] When they come in and say, "I haven't had seizures," we say, "Okay, we're not gonna change anything." So by us not knowing if someone's continuing to have seizures, especially something that might be disrupting your functioning or even just distracting


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to everyday life or impairing quality of life, then we don't know how to op- We're

[00:10:43] Then we're not necessarily optimizing to treat what we don't know is there. So I guess to say that a different way, if a patient says, "I'm not having any seizures," typically, as long as they're not having any side effects from meds, we don't do anything. We say, "Okay, you're great. We'll see you back in three or six months.

[00:10:58] Keep doing what you're doing." [00:11:00] And if they come in and say they're having seizures, then we say, " "Okay let's look at what you're on right now. Let's optimize the meds you're on. If they're not working, let's try another med." So management will get changed, but only if we have all the information.

[00:11:12] **Billy Irving:** And we saw this survey showing that many patients with epilepsy don't believe that they can achieve seizure freedom or that it's not achievable for them. How realistic is that? And what has changed in treatment and therapy? What are we looking at in terms of seizure freedom these days?

[00:11:24] **Dr. Danielle Becker:** So I think that is ... is realistic in the sense of what they've known in the past. So we have over 30 drugs on the market. And really, prior to 2020, all of the medications seemed to be pretty equal in the sense of maybe they would make two-thirds of patients seizure-free. But according to literature by Quan and Brodie, and also Chen, Quan, and Brodie, both in 2000 and 2018 publications- Despite newer drugs coming on the market, the same amount of people were developing drug-resistant epilepsy, and drugs were not working for them.

[00:11:56] So it's understandable that a patient may have been tried on multiple [00:12:00] drugs, and they haven't worked. So why would they think now if something new comes to the market, it's gonna change? And that's what did happen. So newer medications came to the market.

[00:12:10] And so now we're coming to patients and saying, " Okay. We have a newer drug on the market," it has two different mechanisms of action. It may work different than what you've been on before. Let's give it a try."

[00:12:23] But rightly patients might say, "Whoa. You know what? I've already tried four or five meds. I've been There, done that. I always try a new drug. It's an extra drug. Then I have more side effects. I don't feel well. I have worse quality of life." And sometimes they'll say, "Yeah, you know what? I, my seizures are better, but now I'm sleeping all the time, and my quality of life is horrible."

[00:12:42] And so there's this fine balance of trying new medications, potentially taking medications off that weren't working before. But the idea is that newer, innovative therapies are coming to market, and some of them are providing more hope than what patients or what people living with [00:13:00] epilepsy have seen in the past.

[00:13:02] And it's up to us as providers to be able to provide some of that education. And also Landis, with her podcast, she's also spreading so much education and probably in a more understandable, approachable way. So we are partners in this, and just saying, "You know what? Newer options are coming out. And even if options haven't worked in the past, don't give up.

[00:13:22]

[00:13:22] **Dr. Danielle Becker:** There, there May be hope for you." There are newer medications, newer devices newer ways to look at nonpharmacologic things. And we as a community are always trying to get better. We now, There's some development of potentially disease-modifying therapies, genetic therapies. But the point I think that's most important is both the people living with epilepsy and the providers caring for those people, we are not complacent, we are not giving up, and we are always looking for the next thing down the road to improve not only seizure frequency but also quality of life and minimize those side effects if we can

[00:13:59] **Billy Irving:** And sorry.

[00:13:59] Landis, [00:14:00] what eventually made it easier for you to be open with your neurologist about how many seizures you were experiencing? You mentioned that conversation you had that was a really great open conversation. Was that turning point?

[00:14:09] **Landis Weidner:** Oh, absolutely. As soon as I, as, as I said to her, "Hey, listen I, I think I haven't been, I haven't been communicat- I haven't been telling you about this."

[00:14:16] Especially with auras because auras, y- they are technically seizures, I know that, but they are also the start of a larger seizure for me. So if I just have the aura, I would sometimes write it off as not even being a seizure, and it took me a long time to even understand it was a seizure.

[00:14:34] And as soon as I think, as soon as I communicated that with her and was like, "I haven't been, I haven't been telling you about these things," because I did... Once I realized what they were, I didn't think they were a big deal, and she was like, " "Oh no, this is, yes, this is a big deal."


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[00:14:44] And now Our appointments, she a- she asks. She's like, "Okay, so even, include auras when I'm talking to you about these things," and it's just m- a much more... I feel like our friend- or friendship. No, we are not fri- Sorry, let me start over. I love her. I would love to be her friend.

[00:14:49] I am... Oh, sorry, I'll give that two to three seconds.

[00:14:49] I feel like our partnership has grown so much, and I just know and I empathize with so many patients who also have these communication gaps [00:15:00] with their doctors. And again, just looking at that survey, I saw that so many people have it, and the people that I talk to as well will talk about their frustrations and communication mishaps.

[00:15:13] and sometimes it's not... And I don't think there's any side to blame on that. I think it's just having conversations like this, putting data out there like this survey to show people that you are not alone. This is very common. And that helps start bridging that gap to- so that someone can take the step forward and say, "This is happening in the doctor's office," or, "This is not happening in the doctor's office, so let's start."

[00:15:36] And I just hope it helps people feel less alone to know that they're not the only ones experiencing this.

[00:15:43] **Billy Irving:** Dr. Becker, what should neurologists be asking besides, "Have you had any seizures?" How do you think neurologists can handle driving those conversations honestly without discouraging patients from reporting their seizures?

[00:15:54] **Dr. Danielle Becker:** So I think it's important to understand why we're asking these questions and what these questions [00:16:00] mean for management. So as I had mentioned before, and as Landis just said too, y- you, a patient may not realize that was a seizure, right? They might just think, "Oh, I felt a little bit off," and may not realize that's the start of something, and then it often can grow.

[00:16:14] So the first thing is educating different parts of the seizure, and then explaining why we wanna know everything. And so And what we'll do with that information. And so I think it's important to say, when a patient comes in, and I do the same thing, I'll say, "How are you doing? Have you had any seizures?"

[00:16:31] And, the First time we meet someone, we'll ask them, "Ex- describe exactly how your seizure starts. Do you have a warning? Is anything the same every single time? Okay, then what happens? Even if you don't see it, what do people tell you happens? Do you bite your tongue? Do you urinate on yourself?

[00:16:47] Are you confused afterwards?" And a lot of times we'll write it down in our notes. And so we ideally should know what the person with epilepsy has experienced and/or if someone [00:17:00] comes with them in the clinic, what they see as well. So the idea is for us to actually ask pointed questions. So have you had any seizures?

[00:17:07] Have you had any déjà vu? Have you had any, rising in your chest? And a lot of times it's hard because I will try to explain what some of those mean. But saying, I haven't personally experienced this, but according to when I talk to other people living with epilepsy, this is what they tell me.

[00:17:20] Have you experienced anything like this? So giving examples, putting it, in, exactly as Landis had said as well, in, in the setting that you're not alone, right? This is what other people tell me as well. Are you experiencing this? And then explaining that, the reason I need to know these things is because I want to get you on the best treatment regimen.

[00:17:38] I want to try to stop your seizures. But at the same time, I do recognize that it's not just about seizures, and side effects are a big part of it, and side effects people live with every single day, whereas they might have a seizure once a month. So the side effects in itself, the, and the cognitive effects of these seizures may be worse than the seizures themselves.

[00:17:56] And so what I al- often will say is, " We are a partnership," and I love that [00:18:00] Landis used that word too, because it is. I cannot give you the best care if we are not partners, and vice versa. I don't want to tell you something that you don't want to do either. We have to come up with a plan together, because that's the best way to make sure that you're getting the best care for you, individualized care for you.

[00:18:14] So I'll say, "We are partners. I'm going to give you some information, but we're going to make this decision together. I don't want to tell you anything that you might not want to do, and I need you to feel that you have some, that you have control over this decision-making process as well. We'll talk about the side effects.

[00:18:28] I'll give you my opinion. If I feel strongly, I'm going to tell you. But we're going to come together to figure out the ultimate plan. But my goal is not just seizure reduction, but also quality of life. I want to minimize the side effects. I want you to live. And I know that when you have the seizures, they are debilitating.


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[00:18:46] But I need to make sure in between the seizures that you have the best quality of life you can."

[00:18:51] **Billy Irving:** And when Do strategies like, seizure diaries or wearables fit into that decision-making?

[00:18:56] **Dr. Danielle Becker:** So seizure diaries I think can be very helpful. And I think that [00:19:00] they are helpful for patients too, because sometimes they may not remember that they had an event or not.

[00:19:07] But if they write it down in a diary and then they bring it to their provider appointment, it's very helpful to be like, "Actually, I had one this day." Sometimes we can look at patterns, especially in women. Sometimes we can realize they're around their menstrual cycle or things like that.

[00:19:20] So diaries are very helpful, one, to help the person living with epilepsy, their memory, and to keep track of it. Two, to help the provider so they know how many seizures there actually are. Three, to look at patterns. Four, to look at potential behavior modification. So if someone says, "Every time I only get three hours of sleep, I have a seizure," or, "Every time I'm, have a stressful life event or I have a, a exam," right?

[00:19:43] Or I had a ... Someone that I used to work with that would say, "When I was out in the heat for several hours or when I had a really big carb load, I would, I'd always have a seizure the next day." So then th- those diaries help us figure out, okay, what are their triggers and how can we avoid those triggers?

[00:19:56] And maybe that will also help reduce their seizure [00:20:00] frequency. And wearables. You had asked me about wearables too. I also think that wearable, wearables can give you a peace of mind. I think sometimes they're a mixed bag because I've had some people get so- some of the watches and there are a lot of false positives.

[00:20:09] And so it would be stressful 'cause there would be a false positive and it would go out to their family. But other people would say, "You know what? I'd let them know there'll be false positives but we're okay with that because I'd rather people know." So I think... and the wearables are getting even better.

[00:20:21] Now there's apps that you can download on your Apple Watch and things like that as well. I think we're still working in that space. Any time someone gets an alert that there might be a seizure, loved one, you know, your heart drops. And there's fear and, emotional changes with that as well.

[00:20:32] And so there is implications to false alarms. But at the same time, I think just understanding the Breadth of what some of these wearables can do and what it can mean. A lot of people will have things at nighttime to try to know about trying to redis- reduce the risk of sudden unexpected death in epilepsy.

[00:20:48] So I think there's a time and a place and a lot of education for them, and I do think they can be helpful, but there are some caveats.

[00:20:53] **Billy Irving:** Landis, in, in your advocacy work, are you seeing a shift in maybe people becoming more open with sharing the number of [00:21:00] seizures they're having with their neurologists or having a better understanding of what counts as a seizure, and maybe having health- a healthier idea of what their goals for treatment will be as opposed to just feeling like seizure freedom is not something that they could achieve?

[00:21:10] **Landis Weidner:** Yeah. I Think people are starting to gather tools to advocate for themselves, I know a lot of people, have expressed that they feel rushed in an appointment, and that's not necessarily anyone's fault except how the system is set up sometimes. And so I think people will then come prepared.

[00:21:29] I, and that's something I share a lot is that, Dr. Becker was saying that, she asks a lot of very pointed and specific questions, which is a wonderful thing for a neurologist to do, but not all neurologists do that. And what I always recommend is keeping not only, I keep track of my seizures in a, just in a paper journal, old school.

[00:21:46] And then I also c- have a journal that I come in with notes that I've taken in between appointments that didn't require immediate attention and didn't require me reaching out to her immediately. And just, [00:22:00] so that I can come in with a list of my pointed questions for my doctor.

[00:22:04] And that's Something that I have passed along to a lot of people in the community who say that's helped them a lot too. Because sometimes you get into the appointment and Dr. Becker has pointed out, our memories can, they mess with us. And so it's really nice when you can just look down at a piece of paper and you're like, "All right.

[00:22:21] This is exactly what I wanted to ask you." And and I'm very fortunate where- my neurologist will say, "This is my favorite part of the appointment. What are your questions? Hit me up." And it's The last part of the appointment. And but then I know a lot of patients


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don't have the space or the time for that.

[00:22:37] Or rather The appointment doesn't have a lot the time for that, and so they'll send a follow-up message to their doctor with those questions after the appointment. So I Think the more people are aware that they are not the only ones dealing with this, the more empowering it is to know that there are tools and strategies and doctors like Dr.

[00:22:58] Becker who, [00:23:00] they want to know this information and are trying to figure it out the best they can. And I think providing, and by providing more information, it's again just helping to create a better picture and a more holistic picture for our doctors, and then help create a better care plan for us ultimately is the goal.

[00:23:17] Even though that does sometimes, as... Dr. Becker, you just said it so well too. You said, sometimes we're afraid to share these things because we're like, "Oh, but we don't wanna change our care plan because we're tired, and it can be a lot of work," and all of these things, you know? And those are absolutely 100% reasons that people cite for wanting to just keep things to themselves.

[00:23:35] But there is a shift in people realizing that the more you share, the better your care, and I literally just came up with that, but I think it's- Mm-hmm a good tagline. It's

[00:23:47] **Billy Irving:** pretty good.

[00:23:48] **Landis Weidner:** Yeah.

[00:23:48] **Billy Irving:** And so just to near our close here Landis what is one thing you'd want every neurologist to hear, and also maybe every person with epilepsy as well?

[00:23:54] **Landis Weidner:** Yeah, I think one, for neurologists, I think, listen to Dr. Becker. I [00:24:00] love, just asking the specific questions I think is huge. I also think, just listening to a patient's experience, I know I'm sure can be very exhausting all day. But, i-validating it as well, even though maybe it hasn't been cited or it, there's no research on it.

[00:24:17] Or, but still saying, "Okay, haven't heard of that. Gonna figure it out," or just at least note it as a part of, what's going on in their care. Because I know people have also expressed feeling like, they've gotten dismissed by their doctors. And I think that's, just something that, no, I don't think any doctor wants to do that.

[00:24:36] And I think it's a very unintentional thing. And I Think just showing one, specific questions, and two, just, kind of validating experience to show compassion. And then three, encouraging questions from their patients, to help encourage their their own advocacy.

[00:24:55] And then for people with epilepsy, I just wanna let you guys know you are not alone at [00:25:00] all. And in this whole messiness of epilepsy. And, communicating with your doctor as sometimes as, 'cause some, not everyone has, wonderful, friendly doctors like Dr. Becker or like mine.

[00:25:09] And sometimes it can be intimidating, and it's pump yourself up. Gear up but tell everything. And share all of the things to build up that partnership, to build up your health and your overall, not just your seizures, but again, like Dr. Becker said your quality of life, and and you'll find it just, that's just the best way to get the best kind of living that you're after.

[00:25:32] **Billy Irving:** Thank you so much. And Dr. Becker, same for you. What is one thing you'd have, you'd like to have every neurologist hear and every person with epilepsy?

[00:25:38] **Dr. Danielle Becker:** So am I allowed to steal Landis' line?

[00:25:41] **Billy Irving:** Yeah, of course.

[00:25:42] **Dr. Danielle Becker:** So just so you know, I mute myself, Landis, so you can't hear me laughing. But that is the best line ever. The more you share, the better your care. That, that says it all. I don't think any of us could have said it better, and I'm sure you're now gonna see this plastered all over because it's so true and it's real, right?

[00:25:59] And [00:26:00] I think sometimes there's this, you have your doctor on this pedestal, and you over here, and you don't realize that you are both humans, right? You are both fighting for the same thing. And yes, sometimes you may feel that your doctor might feel busy or not asking the right questions, and that is definitely not intentional by any means, but it does happen.

[00:26:19] It happens to everyone sometimes. But the bottom line is that we are all... We all have the same end goal, which is to try to control someone's seizures and give them the best quality of life. And so the only way that we can do that is if we have all the information, the good and the bad. So you have side effects, you tell us, and you tell us right away.

[00:26:38] The thing I think that sometimes can be most upsetting is I might start something, and we have MyChart now and people can


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send messages, but a patient may just tough it out for three to six months and not let me know, and then they come back and they've been doing horrible. And I'll say, "I wish I would've known because I could have changed something."

[00:26:57] You can write me, over MyChart. I will not... I can change things in [00:27:00] between appointments. The goals. I think what's most important is for both people living with epilepsy to understand that their providers have the same goals, ideally and also to share your goals in case there is a disconnect between goals.

[00:27:11] But that if we don't know what's going on, we can't potentially change it for the better. And even if you're scared that it might get changed for the worst, tell us that too. Say, " "Listen, I haven't felt well. I've been sleeping all day, and I didn't say anything because these are the least amount of seizures I've ever had, and I was scared of what the changes would be.

[00:27:30] But then I realize, this, it's affecting my quality of life." I think it's so important to know that it's not just about the seizures. It's about everything in between, and sometimes that's worse than the seizures themselves because you're living with that every day in and day out. I think also, everything Landis has said, I 100% agree with, right?

[00:27:48] You're not alone. You have a community. You have these podcasts. There's support groups. And be Your best health advocate. If you have a provider who is not hearing you, if you have a provider that's [00:28:00] not offering, a rescue medication, not offering a new medication where you may wanna try a new medication, not offering a, a option that you think might help, or you just think may not be hearing you, be your best advocate and say something.

[00:28:15] M- many of us may not realize, and I think that when we do, it's eye-opening, and we're, " Oh, my goodness," "thank you for telling me. Now I can change something." But if I don't know, I'm not gonna change 'cause I won't know I need to, for both the how they may be interacting with you and/or what they might be prescribing for management.

[00:28:32] So be empowered, speak up. We cannot change anything if we do not know. Know that it's a partnership, know that we have the same end goal, even if sometimes it may not feel like that, and be open and honest so that we can give you and optimize the best care. Open and honest with seizures, but also side effects and how it impacts your everyday life And the more you share, the better your care.

[00:28:52] Quote, unquote from Landis

[00:28:54] **Billy Irving:** It's, that's a good one. We should probably put that in a, an article. But thank you both so much for joining us today and for your time and for your insights. This was really helpful, and we really appreciate you.

[00:28:59] **Landis Weidner:** [00:29:00] Thank you, Billy. Really appreciate you having us.

[00:29:02] **Dr. Danielle Becker:** Yeah, thank you very much for this opportunity

[00:29:07] Yeah.

[00:29:07] That's all. That's good. I think we can stop recording.

[00:29:07] **Outro:** Thank you to Landis and Dr. Becker for sharing their experience and knowledge in this episode of Amplifying the Patient Journey.

[00:29:15] And thank you, our listeners. Be sure to visit practicalneurology.com for more podcasts in the field of neurology.


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