

Seizing Life®, episode 105
Managing Epilepsy with the Stress of The Holidays
Guest: Dr. Eva Alden
(Transcript)

- Kelly Cervantes: Hi. I'm Kelly Cervantes, and this is Seizing Life, a biweekly podcast produced by Cure Epilepsy. The holidays can be a stressful time of year for many people, but when you add a health condition like epilepsy to all the activities and demands of the season, the resulting stress and the potential consequences of that stress can become a serious health concern. Today, I'm happy to welcome Dr. Eva Alden to the podcast to talk about managing epilepsy through the joys and the challenges of the holiday season. Dr. Alden is a clinical neuropsychologist and Assistant Professor of Psychology at the Mayo Clinic in Rochester, Minnesota. Dr. Alden, thank you so much for joining us today. I am so excited about the conversation we are about to have because I think it is going to benefit so many people both across the epilepsy spectrum, caregivers, and just regular folk too. Stress and seizures, we know that they go hand in hand. Not uncommon. Stress is often listed among those big seizure triggers for epilepsy patients. Do we know why and scientifically what that connection is?
- Dr. Eva Alden: Yeah, I think there's really two different processes at play. So one is actually a physiological or a biological change that occurs in your body when you experience stress. So our heart rate tends to be elevated, our breathing changes, and along with that, there's also changes in the chemical signals within our brain. The other part is that, when we're stressed, our behavior tends to change. So we might not sleep as well. We might not engage in coping mechanisms that we typically do like exercise. And so it's really a twofold effect, and all of those things can have an impact on seizure control.
- Kelly Cervantes: Do we have any data or statistics specifically related to stress and seizures?
- Dr. Eva Alden: We do, actually. There's been a ton of studies in this area, and I unfortunately don't have time to quote all of them, but there was a recent study looking at the effect of both chronic and acute stress, and up to 68% of patients said that acute stress was a specific seizure trigger. There's also been a lot of research into psychiatric comorbidities and epilepsy, and so 25% to 50% of epilepsy patients have some type of psychiatric comorbidity, depression and anxiety being the two most common. And, actually, untreated depression and anxiety can have an impact on seizure control as well. And so there's an important relationship there that we really need to work on.
- Kelly Cervantes: Wow, that's fascinating. Continuing in this direction of stress and seizures, I can think of no more time in the calendar year than the holiday season when stress rears its ugly head, and in some ways it almost feels unavoidable and we just accept it as part of the season. And perhaps we shouldn't. Why do the holidays impact our stress levels so significantly?
- Dr. Eva Alden: It's a great question, and I agree with you that we do accept it, but we don't have to. I think there's a lot of reasons the holidays can be stressful. It's really easy to over commit yourself and get overburdened with plans with friends and

family, which is wonderful, of course. However, it can be a lot to take on, and I think it's really important to connect with what it is that you want to get out of your holiday season. So I talk a lot about values work when I work with patients, so what do I value? What's important to me this holiday season? What do I really want to do? And try to prioritize the things that are most important so that you don't put too much on your plate. I think the other big reason specific to epilepsy is, again, people get thrown off their routine, and that can be really difficult to manage, especially if you have to take medications at certain times, for example, and that can cause stress in and of itself. And so it's a cycle.

Kelly Cervantes: That makes so much sense. I mean, I see it in my children just being thrown off their regular schedules, and then throw something like epilepsy into the mix and the effect is going to be tenfold. Do you have tips or strategies that patients with epilepsy and their caregivers can utilize to try and minimize some of those stress triggers?

Dr. Eva Alden: I do. I think one thing we want to think about is, how can we prevent stress from occurring in the first place? And I already mentioned connecting with what you value and trying to prioritize things. Along with that, giving yourself permission to say no to things. If you are feeling stressed, allowing yourself to say, "This isn't a great time for me. I really appreciate the invitation. Maybe next year." So that's step one, is trying to prevent yourself from getting stressed out. Step two is making sure that you have some good tools in your tool belt to use healthy coping skills. So whether that's deep breathing, relaxation techniques like mindfulness. Exercise is a big one. Going for a short walk even for 10 to 15 minutes can really make a big difference in your mood when you're feeling stressed or anxious.

Kelly Cervantes: Those are all incredible tips, and I want to harken back to something that you mentioned before in terms of the emotional mental health comorbidities that are so closely linked with epilepsy, specifically anxiety and depression. Stress isn't the only heightened experience that we often feel during the holidays. Anxiety, depression also get a bit of a steroid boost, if you will, during the holidays, and we feel them that much more intensely. Is there something that epilepsy patients can do to help mitigate these risks, things they should be looking out for?

Dr. Eva Alden: Yeah, I think it's really important to keep that in mind that the holidays can be very triggering, and if you have preexisting anxiety and depression, that might be a time where you're likely to experience a flare of some of those symptoms. So, again, it goes back to having strategies that have helped you in the past, and if you don't have those strategies in place already, working with somebody like a professional, either a psychologist or a psychiatrist, to help you work on healthy coping mechanisms or reaching out to a trusted friend or family member who has helped you before or that you feel comfortable sharing those feelings with.

Kelly Cervantes: And then as a caregiver, what sort of behaviors could they be looking out for in the epilepsy patient, warning signs, if you will, that they're not doing well?

Dr. Eva Alden: That's a really important question, and I'm glad that you asked that. I think if you start to notice that somebody's behavior is really uncharacteristic, they're doing things like isolating themselves more, maybe engaging in unhealthy coping mechanisms like overindulging in food or alcohol even, that might be a time for you to reach out to that person and say, "Hey, are you feeling okay? How are you doing?" Or if you notice they're not meeting important obligations either at home, not managing medications or at work, just asking and being present and showing up can mean a lot. The other thing I think that's important to mention too is if you're the caregiver of a child with epilepsy and they start to complain, especially in young children, if they start to complain more about "my tummy hurts" or "I've got a headache" or "I don't want to go to school", they don't necessarily have the emotional language that we adults do. And so those can often be symptoms of things like depression and anxiety in children. And so those are important things to look for.

Kelly Cervantes: That's amazing advice and thank you. I'm having flashbacks to my own holidays when my daughter was alive and I was extraordinarily stubborn and insisted that we still try and live as normal a life as possible, which often meant travel during the holidays, which can be stressful for anyone. But when you're dealing with medical complexities, medications, equipment, it is elevated that much more. You forget to pack your underwear. You can run to the store and pick up some more. You forget a medication or a piece of equipment and all of a sudden it becomes much more complicated. And I wonder, what advice do you have for patients and caregivers as they are traveling during the holidays? What can they do to better prepare and avoid different crises?

Dr. Eva Alden: Yeah, that's a really important question too. Travel's stressful for all of us. I was just talking to a coworker about this earlier this morning, but when you have a medical condition that requires medication and equipment, it certainly adds a different layer to it. Having a plan in place before you go is really critical. Making sure that you pack your medications in your carry on. Do not ever check them. Making sure you have access to them when you need them. Keeping your medications in the bottles with the labels with your name on it may also be important, particularly if you're traveling internationally. I also do recommend that patients with epilepsy wear a seizure bracelet just to let others know who may not be aware if they're comfortable doing that.

Kelly Cervantes: And do you recommend that patients or caregivers alert the flight crew that they have epilepsy before getting on the flight? I know that was never something that I did, but I also had a very stubborn mentality that I could handle everything. But I wonder if that would've been a better move to make.

Dr. Eva Alden: I think in certain situations it could be helpful. I think if you're traveling, let's take this as an adult and as a child separately, if you're traveling as a parent with a child who has epilepsy or an adult accompanied by another adult and you've shared your seizure rescue plan or your action plan with them, I don't necessarily know that you need to alert the flight crew. If there's concern that potentially a seizure could be disruptive to other passengers, that might be a

consideration. However, if you're traveling alone as an adult or an adolescent even with epilepsy, it might be advisable to alert the flight crew. And I actually learned recently that they do have specific training to recognize seizures in the event of an emergency. And so they're actually well prepared and equipped to address that, if a passenger has a seizure.

Kelly Cervantes: I had no idea. That is incredibly useful information to know and I'm so appreciative that they do receive that training. That's incredible.

Dr. Eva Alden: Yeah, I had no idea either, actually. But they get specific training in emergency response situations to look for certain conditions, and seizures are one of them.

Brandon: Hi. This is Brandon from Cure Epilepsy. An estimated 3.4 million Americans and 65 million people worldwide currently live with epilepsy. For more than 20 years, Cure Epilepsy has funded cutting edge, patient focused research. Learn what you can do to support epilepsy research by going to cureepilepsy.org. Now, back to Seizing Life.

Kelly Cervantes: Sticking on the travel piece, we have seen in the news over and over again about delayed flights and people getting stuck in airports overnight and just these nightmarish travel situations. Are there any protections in place for epilepsy patients that really shouldn't be sleeping on the floor of an airport for whom sleep is so dire and important for the management of their seizures? Are there any regulations in place to protect them?

Dr. Eva Alden: That's a great question that I wish I had a better answer for. I did some research on this and I think in large part, unfortunately, it is up to the individual airline. There are a couple things to consider though. One, people with epilepsy may be protected under the Americans With Disabilities Act. I'm not 100% sure what they cover in terms of this specific scenario, but airlines are required to make reasonable accommodations for people who have disabilities. The other thing that you might want to consider is looking into a travel insurance policy to see if there might be coverage for a hotel in the event of a significant delay or overnight stay in an airport with your travel insurance company.

Kelly Cervantes: I also wonder, we've arrived at the destination, hopefully, all of our travel has gone well, and heaven forbid something happens and the epilepsy patient needs to get to a hospital. And now they are not near their doctors. These are not going to be clinicians that are familiar with their case. What do you recommend? How can you prepare for that situation?

Dr. Eva Alden: Yeah, of course, this is something nobody ever wants to have happen, but having a good plan in place, you'll notice I'm a planner, so I always recommend planning ahead for how you're going to handle that. What I recommend patients do is keep a document either electronically or a physical paper document that has the critical key components of their seizure history, what types of seizures they have, what medications they are on, what medications

they've had bad reactions to previously, a list with their primary neurologist or family doctor's phone number on it, those types of things that might help an emergency medical provider know what they really need to know in the event that a patient does have a seizure and they're not able to provide that history directly.

Kelly Cervantes: I know that I had a piece of paper that listed all the medications that my daughter was on, all of her doctors, and a brief outline of her medical history and that went with us everywhere. I also would research the closest hospital that would be able to manage her care before we went anywhere so I knew in advance should something happen which hospital we needed to get to and how to get there. It alleviated some of my personal stress. There was a plan and I knew that if there was a plan, hopefully you don't have to use it, but it was there if we did need it.

Dr. Eva Alden: Those are exactly the types of things that you should include I think. That's great that you did that and I wish more people did that.

Kelly Cervantes: What about seizure action plans and medications? Who should those be shared with? A lot of people don't want to talk about their medical condition, and it's not necessarily perhaps that they're even ashamed, but it's their personal information and it's no one else's business. When someone is traveling or going out of their comfort zone in that regard, or their safety zone, who do they need to tell? Who do they need to share a seizure action plan with and that list of medications?

Dr. Eva Alden: That is a really tough question to answer because I think it's such an individual choice. I do think that if you're going to have a rescue med, if you take rescue medications for your seizures, there probably should be at least one person who's aware of this and able to give you that medication in the event of an emergency, whether that's a flight attendant or a passenger nearby or a family member at a gathering. But it's a personal decision and I don't think you need to share more than you have to. So think about, what are the essential things that somebody would need to know in the event that I have a seizure and I'm not able to tell you how to help me?

Kelly Cervantes: So, again, pre-planning a lot of those answers so in the moment you're grasping a little less and it's just a routine answer.

Dr. Eva Alden: Exactly, and, unfortunately, for a lot of people with chronic medical conditions, there does have to be a lot of planning ahead to manage that, and it's really important and it does place, again, an added burden that can increase our stress.

Kelly Cervantes: Yeah, it is so much planning and so much to think about, and you're already thinking about so many other things that every other person is thinking about during the holidays or when you're traveling, and it does add more. Do you have

any other tips or advice that you have found that have been helpful in managing these stressful and anxiety inducing situations, especially during this season?

Dr. Eva Alden: Don't be afraid to reach out to others and ask for help. I think a lot of people feel really ashamed and embarrassed to talk about these things, but the more we talk about it, the more we give light to these issues that we all face in some way, shape, or form. And I know it's scary, but people who care about you will show up if you ask.

Kelly Cervantes: 100%. Dr. Alden, thank you so very much for sharing these incredibly useful tips and tricks. I hope everyone is out there making their necessary lists and checking them three or four times before they head out for their holiday travel, or even if it's just down the road to a family member's house, I think your advice of being as prepared as possible and having those answers at the ready can help relieve a lot of stress in the moment for a lot of people. So I appreciate your advice and your time today. This is going to be incredibly useful for so many people.

Dr. Eva Alden: I certainly hope so. Thank you again so much for inviting me.

Kelly Cervantes: Thank you, Dr. Alden, for your insights and advice about managing stress during the holiday season for those living with epilepsy and their caregivers. For almost 25 years, Cure Epilepsy has been dedicated to funding patient focused research to find a cure for epilepsy. Today, we have raised over 90 million to fund more than 280 projects in 17 countries worldwide. As we approach the end of 2022, we hope you will consider making a year-end gift to help us continue to fund the cutting edge research that will lead us to a cure. Please visit cureepilepsy.org/donate. Through research, there is hope. Thank you.

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