

Project Sleep Narcolepsy Nerd Alert
Friends and Family (Season 1, Episode 5)
Transcribed by Mirela Starlight

Julie Flygare, JD is the President & CEO of Project Sleep, a leading narcolepsy advocate, speaker, award-winning author, and Stanford Medicine X ePatient Scholar diagnosed with narcolepsy and cataplexy in 2007. She received her B.A. from Brown University in 2005 and her J.D. from Boston College Law School in 2009.

Lauren Thomas is an advocate, a daughter, and a friend living with narcolepsy with cataplexy. She was diagnosed in 2019 after a long journey with misdiagnosed sleepiness. Lauren loves to share her story and resources to help others make their situation a little better.

Anne Taylor, RN, BSN has over 20 years of nursing experience and is a passionate advocate and mother of a daughter living with narcolepsy. Anne also serves on the Board of Directors for Project Sleep.

In today's episode, Julie talks with Lauren Thomas and Anne Taylor, RN, BSN about relationships with friends and family, both from a patient perspective as well as from the perspective of caregiving for someone with narcolepsy. They cover topics such as how to ask for support around narcolepsy, what is and isn't helpful to ask, and how to manage your own stress and do self care as a caregiver or person living with narcolepsy.

The Narcolepsy Nerd Alert series invites listeners to dive deeper into specific topics relevant to living with Narcolepsy. This is a written transcription of the podcast "Friends and Family" (Season 1, Episode 5) from Project Sleep.

Project Sleep is a 501(c)3 Nonprofit Organization, dedicated to raising awareness and advocating for sleep health, sleep equity and sleep disorders.

All guests and speakers express their own opinions. While medical diagnoses and treatment options are discussed for educational purposes, this information should not be taken as medical advice. Each person's experience is so unique, which is why it's so important to always consult your own medical team when making decisions about your own health.

Julie in intro: How can I get my friends and family to understand narcolepsy? I hear this question a lot. It can be hard to explain narcolepsy and ask for help. And even the most thoughtful friends and family members may not be sure how best to support a person with narcolepsy's experience. Today I've enlisted two amazing narcolepsy advocates, Lauren Thomas and Anne Taylor, to discuss this important topic. Lauren Thomas is a person living with narcolepsy with cataplexy, she was diagnosed in 2019 after a long journey with misdiagnosed sleepiness. Anne Taylor is a nurse and a mother of a daughter living with narcolepsy and also serves on the board of directors for Project Sleep.

Julie: Welcome, I'm Julie Flygare, President and CEO of Project Sleep and I'm out here in Los Angeles. Just want to have everyone say hi really quick, so we have Anne— Hi, Anne.

Anne: Hi, how are you?

Julie: Good, good. And where are you?

Anne: I'm in Northern Virginia right now, outside of Washington, D.C.

Julie: Awesome. And then we have Lauren Thomas. Hi, Lauren.

Lauren: Hi! I'm joining from Rye Brook, New York— And it's right outside New York City.

Julie: We're so excited to have both of you joining us today. Lauren, do you want to go ahead and take us through your experience with people supporting you through their actions first? And then we'll get to communication skills next.

Lauren: Sure. I would say since the— pandemic, I have— I used to live by myself in New York City. So, when I was diagnosed, I lived alone— I feel like my support wasn't, I guess as intimate as it has since became, since I moved home during the pandemic. So, I feel like I didn't really have those conversations, or— confrontations, so to speak— about needing support. I think since moving home there really had to be a lot of conversations. I just kind of wanted to feel understood, and I think that that's something that we all can relate to. But I think that there's a lot of shame, especially for a person with narcolepsy when you know, they're in an environment with other people that aren't typically— I mean, anyone that's you know, kind of used to seeing their sleepiness, seeing their cataplexy— seeing their moodiness. That, it was really important that, my family understood and I thought it was really sweet that they all definitely went out of their way to look for resources. I can't remember if it was my mom or my grandma but they gave me Julie's book, and you know, a lot of my family members have read it and now friends have read it and got to hear about Julie's perspective, which is even how I got connected with all of my new friends. Different podcasts and, you know, my dad will— look up YouTubes and even through his work now, he— is really— kind of all in— on sleep advocacy. And, I don't know, it means a lot to me. Just to have them do their own research and then also to— be able to kind of, I guess observe my daily situation and just— see that— yes, it kind of comes in waves and everything is different, if they kind of just even have a baseline of, it's a neurological disease that I need to take naps and I can't really help it and— I think it just makes me feel— safer, more protected, more loved and supported.

Lauren: And then just being able to participate in World Narcolepsy Day was I think the first event that we all really participated in as a family. Just kind of activities like that, have just brought us together more as a family, not even just as a support system for me personally. But my older brother it's just like, they're activities that just bring us closer together and make us support one another and then kind of spark— other conversations about how one can best support each other. My mom's definitely the main caretaker of the family, as I'm sure Anne can relate to that, as well— but there are times when you know, I'm really tired and need help, but I'm also aware that she's really tired, even though it's not the same as my tired— there are definitely been conversations where I need to be respectful of that, and— we both kind of have had to work on our communication, and understanding of, it may be different and everything is valid and, support— and— communication— it's just kind of, I think, the baseline of our successful quarantine.

Julie: Have you— had anyone attend doctors appointments with you?

Lauren: Yeah— definitely in the— beginning, my mom normally attends the doctors appointments with me. My dad definitely— if there's ever any, you know, hospital stays— he's really great for the over night support. But for the— day-to-day, my mom is definitely with me for, you know, my sleep study and early appointments and if there ever is, kind of a time where, I am feeling extra sleepy or I really didn't get sleep that night before— sometimes I'll give my mom a heads up and say, you know, hey I'm sorry you know, we didn't plan this, but— I'm not sure if I'm going to be able to comprehend anything that's going on in this appointment. Can

you come meet me here, or can I put you on speaker phone? Just to like, make sure that everything's checked out, and— 9.9999 times out of ten, she'll drop what's going on to make sure that she can be my advocate. And, it's really helpful just in terms of my memory and I think just the effectiveness of the appointment.

Julie: Yeah. I actually haven't ever had a loved one attend a doctors appointment with me— probably 'cause I was further away from my family, physically, when I was diagnosed. But, I've heard so many good things about that experience. Also if you have loved ones that don't quite get it— [laughing] that this can be a way to hear a medical professional, 'cause a lot of people hold medical professionals, like, in such esteem. That if you're face to face with them, that that can really— help some people— come along in their journey of getting it— [laughs] and I obviously, if anyone's read my book, they know how much the Narcolepsy Network conference meant to my dad and how that was just the thing that clicked for him. Was seeing other people with narcolepsy— which was separate than hearing about my experience, it was actually him— meeting other people with narcolepsy that clicked for him— About the condition, so that's interesting too, that it's like, actually sometimes better to— learn from other people [laugh] with narcolepsy. And of course, support groups—

Anne: I just want to say, there's just so many things I can relate to— I'll— quickly I want to say the podcast, we very often just play them out in the house, and— Then everybody can listen in with, whether they're doodling, or drawing, or— cooking at the same time, but— there's so much power in hearing other people's stories. Because exactly what Lauren said about— not every day is the same. And you can only understand as a caregiver and other family members that not every day is the same if you've heard that from other people too. 'Cause then you know it's not just, you're, in our case, our child. So that just helps a lot. And you can tune out if you don't want to listen, but— especially for my husband it really benefited that he listened to these different podcasts, and— some of your programs that you do on Project Sleep, it just— brought the picture a little bit bigger for us, and— And to hear about other people and different age groups, when you have a child with narcolepsy it's so difficult not to look too much on in the future. And when I worry too much about the future, I always think about that you, Julie, told me, just worry about the now. And so I— I keep telling myself that. But it's— it kind of coming with the role of being a parent— you wonder about how's the next step going to be— how's college, how's the next phase in life going to be. In regards to the doctors appointments, because— Josephine is 16, she's still a minor so I have been going with her all along. But I have deliberately the last year started to prepare her for each appointment 'cause I want her to learn— and she's already doing such a great job— on how to advocate for herself. So we talk about before the appointment obviously, and then I love this telemedicine, it's so convenient and it's great and you don't get tired from driving to the doctors appointment.

Anne: But we have done a lot of preparing before the call— what is it that we want, what goals do we have? What is it that we want to talk about, maybe even writing it down— and she's starting to— take over and start to talk to the doctor about, this is how I feel, and— what could the next step be— and she's also learning that medication is just only a part of the— so-called treatment, but it's not— there's not a cure, and very often she is also learned now that— it's individual and how does it— how it works for somebody else might not work for you— and deliberately I want her to feel that empowerment, that she's also in control of the next actions, and I know that the better— I teach her now, how to deal with the healthcare system, the better off she will be when she becomes an adult. Unfortunately as a nurse I also know all the— potholes and the parts of healthcare that's not working. So I'm also in the process of making a folder for her with copies of— all the labs and all the stuff that she's gone through, because— not only like Lauren said, can be a day where you just have a foggy mind— but it's also difficult to remember what maybe happened a year earlier. And then also take note the doctors don't talk to each other. It is your job as the patient to make sure that X has talked to Y. That means

that you need to know the fax number, the phone number, the information of the next doctor. And that can be so overwhelming when you're at the same time are battling such a debilitating disease as narcolepsy, so I— I look at that, that that's part of my job— and I hope that I can send her out into adult life with some— good tools.

Julie: And when you're done with that, can you come do mine? Because—

Lauren: Yeah— [laughing]

Anne: Yes I'll go with you to your doctor appointment.

Lauren: And that's such a gift for her— that I am not sure that she'll appreciate now, but— having to learn, and organize it all— later on— she'll be such a step ahead.

Anne: I hope so.

Julie: And you're also just outed yourself as a binder nerd. Are you creating a folder, or a binder, or—? [laughing]

Anne: You know I want to save on paper also, Julie. I'm making an electronic one too, it's just that sometimes it's easier when you're sitting in the office and they— the doctor says, "I don't know," well you can pull it right up.

Julie: Yeah, yeah.

Anne: This test just done on this and this date— here we go.

Lauren: Like all the medications that you've tried in the past, and like— who can remember all that?

Anne: Documentation is the key.

Julie: Before we get to communication skills— I know Lauren, I think you really helped us come up with some of these, so— excited to hear what you might say! [laughing]

Lauren: Yeah! I mean I think it also really helped being diagnosed later on in life— I feel like it's weird to put positive spins on— such a— sometimes debilitating condition— but, I think just having more friendship boundaries and— you know, relationships and things like that, to— and just dealing with sleepiness for so long that, when I got the name for it— I was finally able to just say, like, okay, you know— sorry, you know. I can't make it because I'm sleepy, because of my, you know— my sleep disorder. [laughing] I'd gotten past the point where I couldn't live a double life anymore, it was just out in the open. It was over-consuming for— for a bit there, until I got on medications. So I think it's just— really being honest about kind of where you are, I definitely know you know, being— a woman that— there are definitely like certain times of the month that I know that my body is just not going to function. My brain, my legs, like anything— it's just kind of out of commission. This is a tip from you know, another— person in our community— she says she put a calendar in her phone every month, like, "Your brains about to turn to mush, but don't worry— it's because of, you know— what's going on inside of your body," so I think just even having those alerts in your calendar— and, you can communicate that with, you know, your partner— your parents, um— your roommates. And then, just kind of — if you know that you didn't get a good night's sleep, I think unfortunately you really do have to take the first step, in— communicating what's going on because— unfortunately they can't

just see it on your face. You don't have a bloody nose, they can't just look at you and say, "Oh no, she needs help!" We can present very functioning. I think the hardest part has been to take that first step and saying, "This is going to be a really difficult day for me. I'm going to need help," and then, taking that as it comes, instead of being in complete distress all day. And then ending up in the afternoon really upset, emotional— you know, people are like, "What's going on?" And I'm like, "Well I've just needed help— and this—" instead of just, saying earlier, like— I'm going to need help. But then you get yourself so exhausted, so I think just being able to— say that before it gets past the point of fatigue. Because as we know, when we're— past the point of that nap— I call myself like a toddler having a tantrum, like— there's just nothing you can do about it. I think once you've been able to— put that into action, I think your life can just become a lot more manageable and then— people I think will— start feeling more of a routine and more of a flow in the evening being able to get to notice what's going on and then even what questions to ask once you've kind of started and— but, I guess that— first, I guess, invitation, to— participate in the care.

Julie: It's all such a great point. I think the last one is something that was important to me, people showing up in different ways. That was a little bit more about my outer circle, not like my closest friends and family, but— kind of like your— next level of friends group, you know? And realizing that— they showed up in different ways. So it'd be really interesting for me, I couldn't quite always predict that. Just trying to be grateful for those that did. So like when I hosted a sleep walk on the national mall, I had a few friends show up there that literally we'd never really talk about my narcolepsy. But they could do that. You know, they could—

Lauren: Right.

Julie: —That maybe they don't want to sit and have tea and talk about narcolepsy, but they could show up at an event I was hosting—

Lauren: Yup.

Julie: —And be there, physically— when other friends I was actually closer with, I thought— about my narcolepsy— didn't show up. So— it's just, and I always tried not to see that in a negative way, of those that didn't— but more just, take the love from wherever it comes from and the support.

Lauren: Totally. Yeah like I've had certain friends that, you know— need to do their research and kind of, need to get an understanding— on their own— and then I'll have other friends that text me weekly or you know, frequently, just to kind of check in, ask how I'm doing— ask if I need— any help getting my medications— and then there's other friends that just will donate if I'm doing the Sleep In— and I have other friends that do neither. Which is also fine. And we talk about Grey's Anatomy and our relationship is just as full in other ways. So, I think it definitely had to— be something where I've had to level my expectations— and it's definitely been through trial and error, but now I'm definitely, I think, getting ahold of my own ego. [laughing]

Julie: Anne, is there anything you want to mention?

Anne: I mean, I will live with flexibility with plans. You have to be flexible because not one day is the same as the next. I talk to Josephine a little bit before, of what's going on and I said you know, is there anything you want to tell me about and she said, no you just— always anticipate my needs. And I think one of the things as a caregiver, you guys talked about that when you, for example wake up from a nap and your mind is foggy, or— maybe your mood is— a little bit far from being pleasant. That is— that has been a— a struggle. For us as caregivers. My husband and I, especially, to learn where— when, is it just that you're, just moody or— when is

it that it's narcolepsy. And you never know which one. And I've actually just come to find out, if I just put a big glass of either water or coconut water— something, next to her— after she wakes up— and she'll come 20 minutes later and she'll say thank you. And it's just— also just know as a caregiver that is not the time to start to say, "Hey, did you do your homework?" [laughs] You have to really be flexible and— feel the room a little bit. And— but all those things, are easier to do when you have an understanding of— what narcolepsy is, and how it presents itself. And how each day is different. It also means that you can't— maybe plan, like— a long, long event. Or— maybe there is better to have, before COVID— to have friends over for dinner than going somewhere— because then at least she could withdraw to her room when she just needed to be by herself. All these things, all this flexibility has to be— part of our every day lives. And some days maybe she wants to go and do something and other days it's just, no. I just want to lay here on the couch. And it's not, I can't sleep, but— I'm just going to lay here and just watch TV. And that to the naked eye, for other people, coming in from the outside that don't know about narcolepsy could just present as a lazy teenager. So— when we had in-person schooling I always start the school year of hosting and meeting with all the teachers and the counselors— and I look at it from a professional stand point. I present what narcolepsy is and I give them all these print outs from Project Sleep. But then I tell them, in details about what Josephine's needs are— but those things are extremely important and then I have to re-iterate it sometimes throughout the year. But you need to teach everyone that's involved in your child's life to— to be flexible with the plans, because maybe in the beginning of the school day she's good— but the rest of the day she might look like she's there, her eyes are open— but she's not there. So there needs to be— some compassion and some understanding, so. That can definitely relate to the flexibility.

Julie: Communication! Which maybe we should've started with, and then gone to actions, but — [laughs]

Lauren: Yeah!

Julie: [laughing] I just love this quote, I'll just read this first, "Do you wanna vent, or do you want advice? Just learning now after 40 years on Earth this might be the most important question to ask whenever a friend or loved one is upset." And I just think this has been so powerful for me in the last 10 years maybe, to— [laughing] communicate back, to— very well meaning friends and family, sometimes— That I really, often just want to vent— it's my personality to need to— need to share, into space— and not quite being ready yet, for— fixing. I just love, love, love that quote and just wanted to read it.

Lauren: I can totally relate to that quote and I feel like I've said something similar to people in my life recently. And I'm not sure if it's just because I feel like, we have limited hours of the day where we are wakeful and it's kind of, you know, in different segments, so— I know for me personally, I feel like I kind of have to take advantage of— that time and so, you know, sometimes when— I'm just trying to have a light hearted conversation and just kind of share what's going on, about me, like— I don't need a list of, "Okay we'll let's see now, we'll do this," and "Okay well can we do this," and like, no, like— I'm just telling you what's going on, like— I can't take on more, I'm just— letting you know what's going on. So I think this quote is a perfect way for me to communicate that. Allowing for sadness has— definitely been something that I have leaned into— a lot, and I think— especially having, I think, this— community and knowing that I'm not alone in it, I think has made it easier for me to kind of lean into the sadness. Without feeling like I'm over reacting, or— you know, I'm gonna be judged, because — it sucks sometimes. And then other times, you know you get to do cool things like this, which is great. I think the people that I've stayed closest to since my diagnosis I think have been, definitely the people that I've just naturally felt comfortable being able to ask for help with, being able to be sad with, without— having to think twice about how they may perceive it.

Anne: That's why social support is so important. Well, when you're talking about the fixing versus the listening, Lauren— Here I'm the parent and, and— as a parent we just want to fix things. Okay you're hurting? Okay what can I do to fix it. And I feel sometimes— because I'm a nurse I'm like, okay, yeah well I kind of know at least how some of the health care system is working, so some things I should be able to fix and so I'm really working on, too— I wonder if I should just listen— and not say a word— and— sometimes she'll just say to me, "I'm just gonna say something, you don't really have to answer me," okay. And then you just sit with it. And then you as the one that I'm listening you also have to figure out, where do you then put what I'm getting, right. Can I just filtrate it out and then— but for me the social support is everything. What I'm getting through all of these groups is crucially important because it can be so isolating otherwise.

Julie: Anne I remember you— you said something, too, before about being a nurse, and— there was something that— you sometimes say to patients that always stuck with me, when maybe you couldn't solve anything. But you would say something— "I'm sitting with you—?"

Lauren: Yeah. I'm— I'll just sit with you.

Anne: Mm-hmm, and it actually comes from a place of— daring to be present in a maybe otherwise— uncomfortable situation. But just that another human being would sit with you— just reduces your isolation instantaneously so sometimes you might not have any good words — any band-aids to put on. So it could just be, "I can see that you're upset. I'll sit here with you." And— then that's just it.

Lauren: It does make all the difference, from someone that's been sat with.

Anne: Mm-hmm.

Julie: I love that. I'll just add— avoid the temptation to make it about you. We have a quote here on this next one which goes to this point very well— "When life gives you lemons, I won't tell you a story about my cousin's friend who died of lemons." [laughing] We all have such a desire to connect with each other and— having had my dad pass away this is— probably the example for me where it mostly comes up. When someone else says something about having a dad pass away, my instant— I want to be like, "me too, me too!" But it's very hard— but I've learned to stay present with someone and not make it about me— and stay present with them — based on my understanding of having that— but about, keeping about them. And not transferring it back to my own experience or my cousin's friend's experience, or— or trying to relate in that way. It can sometimes— it can switch it, you know, away from— supporting someone that's having that moment of, desiring their support— and not supporting you back, or— [laughs] learning about your cousin's friend, or— anything like that, so. I just thought that was a good quote about that, and a good reminder.

Julie: Communications about things to say.

Lauren: So I prefer, "How are you feeling?" Rather than "Are you okay?" Personally, that's kind of, I guess just a little tip that I have, because— Generally like, am I okay? Like, no. I'm exhausted, I'm so tired. I'm [laughing] you know, like, in pain— I feel weak. I can't see straight. But like, how am I feeling? I feel like, just— allows for such a broader— share of— positive emotions. I just think, "Are you okay?" Honestly just doesn't seem as compassionate, in my opinion, as like, wanting to know the whole spectrum of what's going on. Because I can't answer that in a good or bad sort of way. I think being able to offer, "If you need anything, this is available for you," instead of just saying, like, "Hey, you should go do this," because I think

sometimes people try to be really— helpful, but sometimes they may over step a little bit— instead of just offering what’s going on and then I can use my own sense to feel what’s going on with my body— to use a resource that’s very generously given, I’m very grateful for. And then also just acknowledging that like, you don’t really know what to say but you want to be good, like that— an amazing, honest, supportive thing to say to someone. But I feel like it really also goes with the just sitting with you.

Anne: Yeah. I agree with you. I’ve done the mistake, as a mom to say, “Good morning, how did you sleep?” And that’s not— not such a good thing, and— the answer most of the time is, “I have a sleep disorder, what do you expect?” “Oh, yes, that’s right— I’m so sorry, I’m so sorry.” But you learn from your mistakes.

Julie: That’s probably good practice— I feel like people talk about sleep in the workplace— you know when I was working full time outside of this job— and people were like, “Oh, I didn’t sleep well last night, I’m so tired,” and I honestly have found that I can’t personally, I can’t act — at work especially, how I feel.

Anne: I know.

Lauren: Yeah and then this one, “You’re so lucky you get to take naps,” it’s just kind of, I feel like there are some things that are almost like word vomit when people are trying to connect with you— about you know, what’s going on. And you’re like, “yeah I have narcolepsy, I have to take prescription naps.” Instead of like, hearing you have a neurological disorder that takes away time from your day, because you need to go rest— somehow they hear, like, “Oh! You get to take a nap!”

Anne: Yes.

Lauren: Like, naaah. So I think that also is just kind of goes to the more, like, are you actually— listening and absorbing to what I’m saying, or are you just waiting to say something positive?

Julie: Man, there’s the quote of the day. Sorry, I— I just, like—

Lauren: [laughing] I think we kind of covered a lot of these, but Anne— the one not to talk, that’s a good one. I feel like you had some—

Anne: Yeah, and then there’s days where you feel like you have the energy to explain it to everybody— I have often hear if Josephine is sleeping in my lap, out in the public space, it’s been— “Oh my gosh, that must be so nice just to be able to fall asleep even though that you’re out with so much noise,” or— “Oh wow, she’s just sleep— dozing away, isn’t that something.” And then there are days where you want to say something and then there’s days where you just don’t have the energy and you just smile and wave, and you’re like, okay whatever. And then I think, that’s okay too. Because I can’t be— teaching every day and— You have to also choose your battles.

Julie and Lauren: Yeah.

Julie: We’ve kind of talked about this, I think— when not to talk. Not after a nap. [laughing]

Lauren: Not after a nap. Not on just waking up—

Julie: Not late at night, for most people.

Lauren: Yes, not that.

Julie: [laughing] Not too early in the morning. [laughing] So, a lot of things.

Lauren: What'd you do today that made you feel good? I think that's something that I even try to ask myself every day. As someone that has a chronic illness, like that is like, it is really important to check in and make sure that— yeah, like— this day was great! I wouldn't want to not have this day, and like being able to— keep it in check and keep it in perspective, and then — if there's times where there's nothing that made you feel good that day and you maybe you have a couple of those days in a row— maybe like alert one of your friends, your family members— if you have a therapist, it's maybe time to seek a therapist. Some of the support groups, but. I think even having that kind of check in with yourself can put you in touch of the times when you more need support, and the support's there.

Anne: Yeah. I agree with you.

Julie: Okay. Supporting the supporters, because— I think every relationship's a little bit more complex. Kind of made an assumption through this, that— one role or the other that we each play— so sometimes we all are also supporting other people— but when we do think about this as far as — the people that are taking on some more of the caregiving— Anne, do you want to talk about how you manage? 'Cause it sounds like you're a super mom doing— quite a bit— and I'm ready for my binder after you finish, um—

Anne: [laughing]

Julie: For yourself—

Anne: It's on the list— I'm not a super mom, I'm a human being with a million flaws like everybody else. I'm a work in progress, I'm— working a lot on, and I've been working on for many years, to remember to take care of myself too. And I think it's important to pinpoint that because nobody here is a super human. And— and— humans have flaws and I have as much physical and mental health like everybody else too. Once I kind of get to 8pm, it's kind of like my clock goes out. I have nothing more to give. And— my family kind of knows that, too— and — so I can do most of all my good advocacy and fighting for my kids and my loved ones during the day, but once I get hit, like, 8 o'clock, I just can't do any more. It's like as if the garden work or something that's really important for me— but for me sleep is super, super important. When my chambers are empty of supporting everybody else I have to really remember to get my own good sleep otherwise I can't. And I— you never know what the next day is going to bring, right.

Anne: I have some really, really good friends that I can talk to— and so that that helps a lot too — getting fresh air, remember to get some sunshine— and eat healthy, and— all those good things. And I tell myself, you know, you've done good today.” And that's not because I want to speak myself up, or— pat myself on the shoulder, or anything, it's just that— I reached the goal. If it was the doctor's appointment, I got what I wanted. And now I can see improvement. Great! So that works. And then I do like you told me to, Julie, not to look too much ahead— into the future, and just deal with the— with the here and now. For me— I needed to— kind of early on, find out what can I do— that can help other families. Because I realized that Josephine was lucky that it only took— maybe, three to four years for her to get a diagnosis. But all the years leading up to it, there was other things in the school system that I had to advocate for. And I still have nightmares about this, just thinking about how many children—

that are sitting in the lower education school systems, that— potentially have narcolepsy but are just— being labeled with all kinds of other diagnoses.

Anne: So I'm hoping that the more I learn and the more I can advocate in to the public space that I can hope to bring about some kind of change. And— the picture that you see there is, I went with Julie and with Project Sleep and a whole bunch of other super brave advocates and — scientists, and health care providers— to Capitol Hill, two times. To advocate. And that has just brought me so much gratitude and empowerment. The feeling, that telling— my family's stories— can bring about change— made, it just— filled my inner bucket so much and made me feel so incredibly empowered. And I— believe and I met that in healthcare, too— other caregivers and supporters, there are all kinds of other diseases, they feel the same way— if you can do something where you know you can bring change. Those people before me, all the work that you have done, Julie— you made a path. That I'm now walking on, so it's my job to continue that path and to make it wider and— and include more people.

Anne: And then— I also really hope that when Josephine becomes an adult that she knows that all of you and this wonderful supportive environment of other sleep advocates and people living with narcolepsy, they're going to be there for her. And so, it's really important for me that part of my upbringing of her and giving her the advocacy and the power, it's for her to continue a life living with narcolepsy. 'Cause currently with no cures, this is probably going to be her trajectory for the rest of her life. There's a group of people out there that's going to help her. They're going to help her also professionally, and— so I hope that my work will help her and it will help everybody else that are not diagnosed yet.

Julie: Thank you for saying that about the advocacy, you know, and I think some parents that approach Project Sleep— really, new after the diagnosis, I always also, try to have people recognize that, first to take care of their own family a little bit— before doing some of the public advocacy. Because— you know, that anger— you can leverage that into action. Advocacy will always be there. And these opportunities will be there, and I love hearing how much those have meant to you, Anne. That first point was something from your experience, Lauren. The deep breathing.

Lauren: Yeah, so the deep breathing I've gotten into. Taking a deep breath and— holding it in — and then letting it out. And it really does help center myself. I've also kind of gotten into a technique called grounding. I go outside and— take my shoes off— you know, when I lived in the city I couldn't do this, so here I take advantage outside of my parent's, 'cause you know we have a backyard of grass. You know, stand in the grass. Take some deep breaths in the fresh air. For me actually if I'm having a really foggy— foggy moment, just kind of, centers me and kind of— at least gets me to be able to— figure out what the next task is, what needs to be done— stop myself from snapping at someone because of my own sleepiness.

Julie: I just wanted to remind everyone, kind of what we've been talking about is that, a lot of this is too heavy to carry alone. And to just reinforce through all of this that you deserve support— and we hope you feel that. But also to remind everyone that despite your best efforts, some people may not get it. And so, it's not your fault— if that happens. We all probably experience that to some degree in our lives, in different ways, and— even myself, I think you'd think, oh, Julie— she wrote a book— she knows how to communicate— and I've had some family members say that I don't— [laughing] communicate very well— about my narcolepsy, [laughing] so— finding people who do get it will be invaluable and so— often sometimes that's other people with narcolepsy in this community.

Julie: Some resources— we just always like to remind people of the different organizations that are out there. Project Sleep is one of them but there are other great non-profits doing

incredible, important work as well, so. We'll always put these in our resource guide, and for international organizations please also check our [World Narcolepsy Day](#) webpage, has— 27 different organizations around the world. And this is just one— I'd love to hear if people have other ones, but this is a book specifically that I think can be helpful— it's called "[There Is No Good Card for This](#)" and it talks a lot— a lot of different kinds of adversity. And for me it also talks about infertility which was something that some of my friends have gone through, and— I thought that was helpful for me. So there's a lot of different kinds of adversity talked about in this book, including illness— and loss— of different kinds, so— I think that's a great book.

Julie: There's a technique called [Nonviolent Communications](#) technique and there's a lot of resources online about it— and it goes to some of what we've been talking about, but can help people— communicate in different and, possibly— healthier, ways— so, um— we don't— we're not going to talk about it too much— but just, if you want to look that up— you can look up more resources about Nonviolent Communication technique.

Julie: Your support of us also is very, very meaningful. This community shows up for each other in a way that is so deeply special. So, thanks for everyone for tuning in. That is a gift to all of us. Thanks for our esteemed guests! Bye for now everybody.

Access and download the Friends and Family toolkit [here](#).

The [Narcolepsy Nerd Alert](#) series invites listeners to dive deeper into specific topics relevant to living with narcolepsy and are available in many formats to [listen](#), [watch](#) or read.