



Project Sleep Narcolepsy Nerd Alert
Narcolepsy Road Map (Season 1, Episode 1)
Transcribed by Mirela Starlight

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In today's episode, Julie lays out a roadmap for navigating narcolepsy. Whether you're newly diagnosed or have been living with narcolepsy for longer, it can help to know some of the basic education around narcolepsy. Julie lays out information regarding the medical experience, social experience and internal experiences of being diagnosed with and living with narcolepsy, while also taking care to inform listeners that it's often not a linear path, and suggesting that "narcolepsy doesn't get better— we get better at coping 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 "Narcolepsy Road Map" (Season 1, Episode 1) 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: "So... you're feeling better, right?" This question can be frustrating, as adjusting to narcolepsy is not always a linear process, and can be overwhelming at times. In this episode we break down the narcolepsy journey— into the medical experience, social experience, and internal experience. Each aspect is important, and we hope you walk away with new ideas and resources to make living with narcolepsy a little bit more manageable over time.

Julie: We are so excited to have you with us today for the Narcolepsy Nerd Alert. Today we will be talking about Narcolepsy Road Map. I'm Julie Flygare, I'm the president and CEO of Project Sleep here in Los Angeles, California. So just to get started, when you are newly diagnosed or adjusting to narcolepsy, that someone might ask you, 'oh so, um, you're feeling better now, right?' Like, "oh, you've found your diagnosis, you got treatment. So you're better!" And you know, I think for me at first that question was really overwhelming and really brought up a lot of— kind of, anger. And not at the people asking because I know their intentions were in a good place but I didn't know how to answer 'cause I didn't get better right away. To imagine living with a chronic condition as sort of a linear process where you can just take treatment, and— you're better!— It's not such a linear process, it can be pretty overwhelming. And I'd probably suggest that— narcolepsy doesn't get better— we get better at coping with narcolepsy. And so being part of this discussion today is, I hope— one of those things that helps us get better as we all try to find new resources and tools for living with narcolepsy.

Julie: We talked about a theme of a roadmap and as I was thinking about that concept as we were putting together the materials it is kind of a funny thing 'cause a road somewhat suggests that it is a linear process— you know that you're on one road and that there is the right time and



the right moment for everything and— I think that maybe what we will talk about today is that maybe that's not even the best analogy, it can't quite be one specific linear experience. There's a lot going on. So, in thinking about what we could provide to people at diagnosis, this is how we thought about it.

Julie: First of all, we believe there's a really important starting point for any journey. We truly believe that basic education— basic education about the symptoms of narcolepsy, the treatments available, and some of the different coping mechanisms that people use— some of that basic education is really important. Almost, I'd say— every month, I end up speaking with someone that isn't quite sure they understand what cataplexy is or hypnagogic hallucinations and sleep paralysis. The definitions can be a little bit confusing and so, we do think that a starting point should always be basic education.

Julie: I really love this quote which brings up some of the different aspects of living with narcolepsy or a chronic condition, "Living with a chronic condition is an ongoing process of inner negotiation, between social and medical needs. Shifting between illness on the foreground and wellness on the foreground." And I really love this because it talks about social, medical and sort of our own inner negotiation.

Julie: Because we are big nerds over here at Project Sleep, we thought to break down some of what we're going to talk about today into three areas. So we're going to talk about the medical experience— things about managing symptoms, accessing healthcare, doctors and treatments.

Julie: The social experience, you know basically managing your relationships. You know basically that everyone plays roles. In your own life, beyond being a person with narcolepsy— many of you are mothers or daughters or fathers or sons or aunts or uncles. You are students! You have professional aspects of your life— ambitions, dreams, goals. You're a husband, wife— there's a lot that ends up being a social experience and how narcolepsy ends up being integrated into that. How do you communicate about it, how do you disclose about narcolepsy? So we're going to talk a little bit about the social experience and then also the internal experience.

Julie: So these are things that are happening inside your head— [laughs] not that that doesn't make them important, I think they're extremely important and I think they're underrated. I almost wanted to shift the way we approach this and go from internal to medical, because I think that often social and internal experience isn't as recognized. But for internal— it's feelings, intrinsic characteristics, your own self perception of yourself and what narcolepsy might mean for that self perception when something new comes into your identity— stress management and acceptance of the condition. So those are some of the things that are in that area.

Julie: So, when we talk about medical experience, again— these are just some things to get you guys talking and thinking out loud, and help us brainstorm— these are not an exhaustive list by any means of important concepts. These are just some of the things that we thought to get started with.

Julie: For medical experience, expertise really matters and not all sleep specialists have the same expertise in narcolepsy or idiopathic hypersomnia. And I think that is— unfortunate, of course. We wish there were more specialists in, you know— every major city of this country— and around the world, right? But it is important to know that the person who diagnoses you may or may not be really a true expert or have a ton of experience in treating people with narcolepsy. And so I do encourage people to think about getting a second opinion. Not in like that, that we

don't believe the doctor about your diagnosis maybe. Maybe that's the case but, just in gathering more information and more opinions. And one of the things that makes me always kind of, I don't know—[laughs] feel a little bit uncertain? But this is the truth about science is—it's an art. Medicine is an art. And part of that I guess is that some of the best specialists, even—in the country I'd say—don't always have the same opinions. That's how varying people's opinions can be. And so I think that's just really important to think about—getting an extra opinion, at any point in your journey. And to feel okay about doing that. I think often we think that, you're in a relationship with your doctor in which like, if you were to seek a second opinion that you're somehow breaking up with them, or—you know, causing some sort of, uh... but you are not, y'know, dating your doctor. You don't have to worry, it's not a break up. So, just be empowered to pursue more medical attention.

Julie: Finding optimal treatment with narcolepsy is a journey. Okay, I'm sorry I have so many dating analogies, but—I think that when you are newly diagnosed you might want the first treatment to be the right one. Somewhat similarly to online dating [laughs] which is something I've been dealing with. And of course the first guy that you meet through online dating you just really want to be the one, right? Or, the first person you meet. Of course you want it to be the right fit. Right? Like, you start this new treatment and that's the one that you hope is it. And that's just not always the case and I think it's really good to know what else is out there and to never think about a treatment as—going to be something that is for the rest of your life. That you can try new things and see how they impact you, for better or worse—and then look about how you might negotiate other things in your life to make a certain treatment a part of it, or not, over the long term. Incorporating napping, lifestyle changes and social support—I think that is just really underrated how much other, you know, aspects of coping—can be helpful, beyond traditional medications. These are really important for a lot of people, in different ways.

Julie: The last concept here we want to talk about is cure culture. Which is the idea that in our society there is an emphasis on feeling better, on getting better—and we're all for looking for different tools and ways to be better. But there is also this overarching feeling—that we should somehow be able to cure or—get fully better. And so I just love this quote from Toni Bernhard's book 'How to Be Sick' which is a very buddhist approach to dealing with illness. And she says, "I blame myself for not recovering. As if not regaining my health was my fault. A failure of will, somehow—or a deficit of character." And I just think that is, really—an important part. Where there is so much emphasis on—doing everything that you can, to be better—that sometimes that ends up making us feel like we're not doing enough.

Julie: Okay, so talk a little bit about the social experience. Such an underrated part, I think as well. Often I think there is a feeling, I know it was true for me, and I hear it from a lot of people that they have narcolepsy and they're trying to explain it to others in their life—whether that is to their family members, or their peers—at school, or work. Or, you know, supervisors—teachers. So many people [laughs] to try to explain narcolepsy to. And often we don't quite always understand it or how best to articulate it and—in future podcasts, you know, we will talk more about communication skills, for sure, and—best practices and all that—'cause we're nerdy!—[laughs] But for today we just want to kind of emphasize the point that—there are going to be people who don't get it, and that's just a really big challenge. And we don't necessarily think we have solutions to every one of these things we've listed here, but—it's an important part of the experience to somewhat be prepared for, I think. And to know that, I think over time, you can find—new people in your life who might get it. Whether that's other people with narcolepsy's through some of the great narcolepsy communities that are out there, or... Even other people who have faced different kinds of adversity. So I know one of my best friends when I moved to D.C., we were in a writing group together and she had experienced a tragic

loss of a daughter in her life. The overlapping experiences, especially the social experiences and the isolation we felt, all at once— was very similar. Remains one of my best friends to this day. So I think there is, you know— important to know that not everyone will get it, [laughs] and that I think no matter how well spoken you can be and no matter which best practices we share, at the end of the day some people might— never get it. But there will be new people that you will find in your life that do.

Julie: Emotional versus a transactional approach— something that has been increasingly important to me, to— think about, sometimes we want people to get it, in a way that's— emotional. We want them to end up, maybe seeing the light, that— this is such a serious condition!— and, I'm so sorry you have to deal with it! And you want a big hug and maybe like a good cry [laughs] like the moment I had with my dad after attending Narcolepsy Network's conference, where— he just got it, right— and we had this emotional bond. But I do think there's also something to be said for having, with certain people— like in employment or school situations, having a more transactional approach— and what I mean is that, having an HR person— who's never heard of narcolepsy before, or doesn't really know what it is— and I need to get an accommodation from them, that I'm not looking for that HR person to get it in the same way that I wanted my dad to get it. But I just need to give them the information that is necessary in order to get what I need. To be very goal oriented and very transactional about how I approach— interacting with that HR director, or, if it's a school administrator— about accommodations. And that's really hard for me. I know when I had HR experiences, sometimes I would walk away from the most basic meeting with the HR person, you know, of like— checking out the different rooms where we could put a bench, so I could nap— no matter what— I walked, and I would walk back to my desk and I would often cry. Because I felt exposed, I felt vulnerable— in that moment. And so the emotion is always there, but just thinking about some of those, is that I wasn't trying to get that HR person to get it— in the same way that maybe I want like my own family and friends to. But just kind of going with transactional. You know, get what we need here and move on.

Julie: So limited energy expenditure or the spoon theory. I think this is a really wonderful concept that can really help to articulate some of the experience of living with narcolepsy that isn't limited to the basic symptoms. So, often— when I've been in relationships, or even with my family— there's a thought like, when you're trying to plan what to do, and— you know, make plans together. You might think— something like, going to a comedy concert, err, comedy club— you know like, at night. You might not like, be worried that you're going to have, you know, an episode of excessive sleepiness— or an episode of cataplexy at the comedy club, maybe you're actually just like— don't quite have enough energy to do that on top of, you know, going to a different thing the next night and, all this. So I think it's just important to think that beyond the basic symptoms and your experience with those— it's okay to know that, living with a chronic condition can mean— and again, if this doesn't resonate with your experience, that's fine, but— for some people that might mean that there's limited energy expenditure. Or, the spoon theory is a concept developed by a woman with a chronic condition, and— if you're not familiar with that already, please look that up. So for me with some friends and family I could say, you know, they might ask if I want to do something I could just say, "oh, I don't have the spoons today." Which is just a really helpful way for me to say that I just didn't have the energy for all the things. Which our culture very much, you know— wants us to think that we should be doing all the things, all the time.

Julie: So creating boundaries and knocking them down I think are really important for social relationships. When I lived in Washington, D.C. I set a boundary that I would only drive 45 minutes. Could I drive longer than 45 minutes? Probably, certain times of day— certain

medication, you know— depending on what I'd eaten, you know— all that, right. But by creating that boundary of 45 minutes, that I could just tell my friends that, it just made it more clear that if it was longer than that, that we'd have to figure out who else was going to drive. And that just helped like create a lot of peace for me— and not having to worry about all the details of something like a longer drive.

Julie: And so you know, since then, when I talk about creating boundaries— it's also good to know that, you can knock those boundaries down— when it makes sense for you. And so I gained more confidence in my ability to know when I need to pull over and so living in Los Angeles, where I can't get very far— in 45 minutes either—[laughs] I was able to change what those boundaries are. But I think they can just be helpful sometimes to present publicly to other people. So that's just one idea.

Julie: And building a strong 'no' muscle, I think a lot of people talk about this, is that we have to prioritize our time very carefully— and that can be very challenging, for a lot of people. People that are caring and want to do lots of different things and we have interests, and hobbies— and people that we want to see. So saying no to things is hard but I think can be important. The thing that I like to explain about this is that we don't always need to explain our no. So if you have to write a friend and say, "I can't make it tonight." I actually believe that you can just leave it at that— and you don't have to always over explain why. Because I do feel that sometimes— it depends on the situation, right. But if I'm going to explain that— further, and say, "it's because I might have cataplexy—" or, "I've had a really rough day, I can't quite make it because, I don't— you know, this or that." Then I think I'm looking for social support back from that person, and if that's the appropriate relationship that's okay, but— for certain people, and certain things— especially more professional environments, I try not to explain my no. You can just say, "I can't make it, thank you for thinking of me." Because the reason I say that is because sometimes if I've over explained, or I've gone into the reasoning, I'm looking for a response— I'm looking for a thoughtful response and if I don't get that, that can be— really disappointing. So, anyway. That's just another concept there.

Julie: Just one more quote, I love this quote!— and it kind of bridges between the two different topics we have, is social and internal experience— but, I can't find who actually said this online but it's— always stuck with me, "I have this weird relationship with my chronic illness where I spend 75% of my time trying to pretend that it doesn't exist and the other 25% trying to explain that it does exist to a bunch of people who don't believe me." [laughs] So just kind of your internal experience of— of possibly trying to— pretend this isn't happening, but then the other percent of your time, like, "this is real!" [laughs] to other people. When I do hear from loved ones of people with narcolepsy and they're— looking to learn more, they want more resources— It just gives me so much hope because I think, that— interest [laughs] is more valuable than anything they could actually learn from resources, it's that drive to learn more— that desire to support your loved one, like— that is so meaningful. Thank you to all the supporters that are, you know, trying to get more educated and more involved and, help your loved one. That's just, amazing— we love you guys!

Julie: So let's just talk about the internal experience— kind of like, thinking about acceptance— and some of the internal experiences, and all these are, really— are very intertwined, right. A lot of our social dynamics end up affecting our internal experience, and— back and forth. So, as mentioned in that last quote, you know, this— kind of this concept of pretending narcolepsy doesn't exist. I don't know if you guys have been there— [laughs] that when you were first diagnosed you kind of just wanted to pretend it wasn't there— [laughs] that was me!

Julie: I think that I thought that if I somehow put narcolepsy in a corner— or brushed it under a rug, I mean I was going to take my treatments, but— I wasn't going to let it be any other, bigger part of my life, okay. It was just going to be this small, little compartment, and if I did that— I, Julie— was not letting the narcolepsy get the best of me. No way. Over time, I think I realized that that approach actually made me weaker— and not prepared, to be the best version of myself with narcolepsy. And so by opening up to learn more, and— think more about my narcolepsy, and meet other people— and become more engaged, it did not make me weaker. It did not mean that narcolepsy was beating me. It actually meant that I was creating a stronger version of myself— and being the best that I could be, with narcolepsy. And that was actually truly winning. So, I don't know if that resonates with people but I think that was part of a transition experience for me. Another concept that I definitely talk about in my book and like to bring up in presentations, is that— sometimes your biggest critic— is living in your own head. I think we've all probably been there.

Julie: And I know for me, before I had narcolepsy, sort of like, negative self talk— was a form of, motivation. I motivated myself— through negative self talk. I'd say, *gosh, you're not doing well enough, you've gotta get out there and go for that run.* And that was okay, it worked well enough. Until I had narcolepsy— and I found that beating myself up in my own head, scolding myself for every misstep— it no longer worked, because I felt that— I didn't have support from other people, the way I wanted— and then if my biggest critic was my own head, it was just kicking me when I was down— is how I felt. And so I just want to bring that up, and think about how you speak to yourself. As much as you can— I know people talk about meditation, or mindfulness. I really like the concept of mindfulness and there's some really neat stuff— I'm forgetting the name of it, we will definitely put this in the toolkit— about learning to recognize your own critic in your head, and— talk back to it. [laughs] So it's a really cool theory that has been really important for me, in my life in general.

Julie: So then the space between health and sickness— I think that there's a lot of inner negotiation of thinking, especially with narcolepsy— especially in our society, that there's a concept that either we're healthy or we're feeling sick. You know, the idea of a sick day— at work, means that you're so incapacitated that you just can't make it at all, right. And I find that living with narcolepsy is living in the grey— between those two things, health and sickness. And it's not always so clear— whether I needed to take a sick day from work. The symptoms would come and go. Some days I might feel terrible in the morning and then end up having more energy in the afternoon and the evening. Other days maybe I started great and then— ended up with a lot of symptoms later in the day. So, just wasn't always that predicable— and, didn't feel that it fit into concepts of, "I'm healthy today, I'm feeling great, got it all together," or, "I'm completely sick, I'm in bed, I can't move," right. And so I don't know if that concept resonates with you guys, but— I think for me, I ended up feeling that, to give myself, grace— or to give myself the benefit of the doubt, sometimes taking sick days— even though I wasn't sure if I was fully sick enough to do so— I love that concept like, a mental health day, too. For similar reasons— it's not necessarily that I'm in bed and have a fever and can't move, but— that it's good to take rest days some days.

Julie: I also feel a lot of the internal experience for people, especially newly diagnosed— is getting caught up in future thoughts, and trying to center people in what they can do now— and not in fears of the future. There is a concept that true suffering is in our fears of future experiences, as opposed to things that are actually happening now. And I think that when you're newly diagnosed you might think, "oh my gosh, I can't get my symptoms under control with the treatment," you know, first drug didn't work— "I'm not cured, and now I won't be able to go to the grad school program I want," or, "I won't be able to drive in 4 years," or— you know, "I'm not

going to be able to take on that career role.” Those kinds of thoughts, I think— I try to suggest— that, you need to see where things go, because there’s just so much progress that can happen, over time. Especially as you try new treatments and different approaches and find what works best for you. That optimal approach, which is never perfect, but— try not to make decisions about your future— [laughs] and as much as you can, try to let that future stuff happen when it happens— and stick in the now, and what you can control now.

Julie: And I think that’s sort of one of the loveliest things that I’ve seen recently is the universal law of impermanence. It’s a Buddhist concept called anicca— I don’t know if I’m saying that correctly, but— that everything is changing, or evolving— and that’s for better or worse— and I think, what gives me hope— is that my experience with narcolepsy really has evolved so much over time. And so, those first— I’d say, two years for me— narcolepsy took up a big portion of my head space.

Julie: Alright one more roadmap analogy— I’m sorry, but I thought of this yesterday. I feel like when I was first living with narcolepsy it was like I was listening to— google maps, or— road maps— you know you have a navigation system on in your car, and you’re trying to have a conversation at the same time, so you’re trying to talk to the person next to you— and the navigation’s, “turn right! in 1000 feet, turn right” and you’re like, ugh, so distracting, go away! That is how I felt, like I felt like every, like— you’re trying to go through your life with narcolepsy and continue forward and then all at once it’s like, “turn left! turn right!” and you’re— it’s just so— it was so overwhelming at first, narcolepsy took up so much headspace— it was so distracting that it was hard to feel like, how was I going to manage this, over the long term? I found that over time it took up less head space, that some of those things became much more routine, right. Narcolepsy didn’t get better, I got better. But things became more routine and it just didn’t consume as much of my time— as it did the first few years. And so, we quieted that navigation system— a little bit, for me. And that’s really been part of what I like to share with people when they’re newly diagnosed— that I know it’s overwhelming right now, and it might be for a while longer, but it might not be exactly like this— how it is right now for you— over time.

Julie: Just have a little nice quote about this from one of my favorite podcasts. We’re going to share some resources and stuff at the end, but— here’s just a quote I love, “This is a planet full of people evolving.” And it’s from the, This is Not What I Ordered podcast, and it was Allison— Sattinger, I guess— who said that. I just think that is such an important thing to remember, that we are always evolving.

Julie: You know when you’re newly diagnosed it’s not like anyone even, like— brings you— flowers or you know, balloons, or— sends you cards— and, yet— something has shifted. And often it’s not visible, right? I know when I was diagnosed, I’d actually— I’d always been on a diet, my whole life, pretty much— since I was like 13, and I’d always been a little bit— you know, chubbier— or whatever. And when I started the narcolepsy medications I lost— some weight. So I actually, kind of looked better than I ever had— by certain standards, which I don’t want to, probably— whatever. It’s a whole different thing. But externally I actually looked, probably— a little healthier— by some people’s standards. But this time my internal experience was, I was not feeling well— and I was trying to figure out what narcolepsy meant to me and all of that experience, so. Just creating more spaces and places— to be able to talk about those things and those experiences I think are important. I think journaling can be helpful too. You know, I love the concept of dance. Like, it really is whatever works for you. Journaling, writing— expressing yourself in different ways. Therapy, support groups— you know there’s just so many different opportunities, depending on what you like.



Julie: I just want to go through a few more resources— I think it's really important to know there are patient organizations out there— Project Sleep is one of them, so you're connected with us. But there are others that are doing fantastic work in this space as well. And so in the United States some of the major leading organizations are the Hypersomnia Foundation. All of these have such great resources— and the [Hypersomnia Foundation](#) is really focused on idiopathic hypersomnia but also goes beyond that. As we are all doing right now they're doing more online. Check out, you know— some of their different events.

Julie: [Narcolepsy Network](#) is another wonderful organization in the U.S. and they are doing I know, online support groups— right now and also some different mini conferences, I believe. They have a wonderful Youth Ambassador Program that helps to train young people to be ambassadors in raising awareness.

Julie: Obviously you're here, so you're familiar with Project Sleep, hopefully— and our programming, and you know— we'll be talking more about becoming a narcolepsy advocate and our efforts in the advocacy space and awareness as well. So we have the [Rising Voices of Narcolepsy](#) program that we hope that some of you will sign up for this summer to train you on sharing your story with narcolepsy to raise awareness.

Julie: [Wake Up Narcolepsy](#) is another wonderful organization, and they have a fantastic podcast called Narcolepsy 360— along with doing some educational events throughout the year, and they also host online support groups. They have quite a robust structure around those support groups online, so I think that's a really powerful program that they've taken on and hope that you will join them for a support group meeting.

Julie: There's international organizations for our friends around the world. I'm not sure if people are tuning in internationally today, but— I didn't list all of them, there's about— I know there's 27 different organizations that are co-leading the World Narcolepsy Day and so I have all those listed on Project Sleep's [World Narcolepsy Day](#) webpage. You can see all those around the world. A lot in Europe— There's [Narcolepsy Africa](#). There is a group in Japan— and Australia— and Argentina, and Brazil. So, really— almost every continent— so yeah! It's just really important to know that those organizations are out there, and a lot of them have really great programming.

Julie: Because we're nerds, we love books— possibly. I don't know. There's different forms of nerdiness. I do love books, so I just listed some of my favorites. Some that are narcolepsy specific, and some that are not. [How to Be Sick](#), I mentioned that one by Toni Bernhard. It is a Buddhist approach. You know, she uses a lot of Buddhism terms which I just think is really neat to learn about— 'cause I love learning. [Sleepyhead](#), by Henry Nicholls is a fantastic book about his experience with narcolepsy but also about the science of narcolepsy. He is a wonderful writer, he is a science writer by profession and Sleepyhead is his book about sleep and narcolepsy and the science and his experience— so check that out. [Surviving and Thriving with an Invisible Chronic Illness](#) by Ilana Jacqueline. I think that Ilana is just a witty writer and has a great perspective and I absolutely love her book that she's published.

Julie: [There Is No Good Card For This](#), by Kelcy Crowe. This is one of the books that has meant the most to me, in my own understanding of how— a chronic condition is one of many things that makes people feel kind of socially awkward— and not know what to do, or what to say. And there are many areas that this book talks about, from chronic illness— to infertility— to grieving the loss of a loved one, and— it really touches on a lot of different aspects, of— some of that social disconnect that happens when there's major adversity in someones life. Definitely



recommend that. It's also very visually stunning— she worked with an amazing graphic designer on that book. Waking Mathilda is Claire Crisp— amazing memoir from her experience as a mother, living with a daughter diagnosed with narcolepsy at a very young age. So, definitely recommend Claire's book about that experience. And then of course— my own, I guess— Wide Awake and Dreaming is my personal memoir. And you know, honestly every day there's always new stuff that's coming up on amazon so another good thing is just to search on Amazon for the word narcolepsy and see what you find and see what you like and let us know.

Julie: Additional resources include Narcolepsy 360 podcast by Wake Up Narcolepsy— a wonderful new podcast they've been doing, I think it's their third season now— super cool. A lot of different perspectives from researchers, to people with narcolepsy and loved ones. This is Not What I Ordered-- that's the podcast I mentioned a few minutes ago by Lauren Selfridge. Lauren is a therapist, by training— or by profession— and also a woman living with multiple sclerosis. So she has a podcast featuring many different people with different chronic conditions and I think just her therapist perspective really is a cool perspective that she brings as a host of that. Also Lauren's website— if you look up, This is Not What I Ordered— her website also has a link to therapists that consider themselves having an expertise in the chronic illness space. So, it's not comprehensive across the country or whatever, but she is trying to collect a list of therapists that believe they have an expertise in that area— which I think is really exciting 'cause that's something that I think could be helpful for some people to have a therapist that has that area of expertise.

Julie: There's the narcolepsy chat or #Nchat on Twitter every month. I believe it's the first Saturday of every month, at 5PM Eastern. And so you just sorta follow along with that hashtag, and they have great questions every month. Prompt questions and it's a great way to connect with people around the world. And also I just, like, really encourage people to follow the hashtag narcolepsy on instagram or tiktok. I'm not personally on tiktok, but I hear there's some great narcolepsy content on there— so, you know— it's just, always— so encouraging how wonderful and how creative people are, increasingly— in creating content that has to do with their experience.

Julie: I just believe in storytelling and that's why we've created the Rising Voices program now so that we can share your stories. Not everyone will get it, but— there are certain techniques that someone uses in writing a book, or— in building a story and we're just huge dorks about that— and love, love love— utilizing some of those best practices in helping you frame your story in a way that will increase empathy and decrease stigma. So, my last pitch there. If you want to increase, you know, your ability to tell your story because everyone's story is like— there's just— so many different ways that people share things and so many different experiences and they're all so important. So we're just trying to do that through Rising Voices now.

Julie: Please if you haven't already signed up for our e-updates— specifically for Narcolepsy Nerd Alert, please do. We're creating— in addition to Project Sleep's big list of everyone that likes to know what we're doing— the Narcolepsy Nerd Alert e-updates are going to be more specific to that group and allow us to email you, to send you the toolkits afterwards and the video links, and so please do.

Julie: And if we have new announcements, 'cause we really do believe this is a community of people that are interested in learning, and again— please do share this because you just never know when you're going to reach someone that needs to know what narcolepsy is. And if this could possibly be that catalyst for someone that's just an amazing thing. Oh! Also when you do



sign up for the news— e-updates, you have the opportunity to write in what future topics you'd like us to cover.

Julie: Well thank you guys for tuning in and we hope that you stay well, stay safe and stay nerdy! Uh-oh, just came up with that one! [laughs] We will see you again soon.

Access the toolkit for this episode [here](#).

Narcolepsy Nerd Alert episodes are available in many formats to [listen](#), [watch](#) or read.