

Project Sleep Narcolepsy Nerd Alert
“Sleep Paralysis + Hallucinations” (Season 1, Episode 16)
Transcribed by Mirela Starlight

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In today’s episode, Julie talks with guests about their experiences with hypnogogic and hypnopompic hallucinations, sleep paralysis and how hard it can be to define the line between being awake or asleep. From being paralyzed for an hour to feeling haunted or seeing birds flying around at work, guests describe how some of the the symptoms of narcolepsy can interfere with and confuse everyday life.

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 “Sleep Paralysis + Hallucinations” (Season 1, Episode 16) 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: Narcolepsy after dark. With terrifying hallucinations around sleep and sleep paralysis, the lines between sleeping and waking can be blurred with narcolepsy. These are under appreciated symptoms, so in this episode we talk about these experiences and how to cope with them. Today we have an amazing panel of guests. Chelsea Cataldi is a world traveler who enjoys creating things with her hands. She was diagnosed with type 1 narcolepsy with cataplexy in 2010 while living in Japan and now she's a Rising Voices speaker with Project Sleep. Kristyn Beecher is a storyteller and news producer from Houston, Texas. She was diagnosed with type 2 narcolepsy without cataplexy at age 24, but lived with symptoms for many

years before that. She's a graduate of Hampton University and a Rising Voices speaker. Connor Baker is a CDU nurse working at Rush Copley Medical Center in Aurora, Illinois. He was diagnosed with type 1 narcolepsy with cataplexy at 20 years old, and now he shares his story as a Rising Voices speaker.

Julie: Hello, welcome to our narcolepsy Nerd Alert about sleep paralysis and hypnogogic hallucinations! We're so excited to be here today. We're going to start with just going over the basic definitions of these terms, and then getting into some— some example stories. So sleep paralysis is defined as the inability to move or speak for a few seconds or minutes when falling asleep or waking up. So this can include a sense of restricted breathing, or crushing weight on the chest and is often accompanied by hypnogogic and hypnopompic hallucinations. Such a long word. Well, what are they? They're visual, auditory or tactile— so seeing things, hearing things or feeling things, or other sensory hallucinations, upon falling asleep or waking up. Can happen while feeling awake, and we'll definitely talk about that— are we awake? Are we asleep? What's happening. It's often frightening and confusing, and common themes include intruders, incubus, unusual body experiences. So, this can also include, you know, floating or flying or— out of body experiences, as well. Had a few of those. And I guess we'll just mention here really quickly you know when we think about sleep paralysis and hypnogogic hallucinations and the difference between what someone might think of as a regular dream or nightmare I know for me like I'd experienced plenty of dreams, or— you know, scary dreams, when I was growing up. But my first hypnogogic hallucination and sleep paralysis experience felt really different, because it felt like it was happening in the very space where I was. And I think that's kind of a good distinguisher between talking about just dreams or nightmares versus these experiences, which is that they are often they are exactly where you are, where you're sleeping, or napping or you know, struggling to stay awake and the things are in that space as opposed to going off in your dream to other places, flying above buildings or, thinking you're at the mall or you know, stuff like that. Those are where you are kind of like in a dream experience, going other places. So before we get to some of the other history though, I just want to— we have some incredible speakers. But we were joking before we came on here that, perhaps this is like the Oscars of hypnogogic hallucinations and sleep paralysis. Our guests are— have very memorable experiences that have really stuck with us. So, if they would be willing to share a little bit of those. Anyone want to go first?

Connor: Alright I can, yeah— that'll work, I can go first. I've had multiple you know throughout the years that I've had narcolepsy and, before I was diagnosed with it I just thought they were really, really, really bad— dreams. But [laughing] one of the ones that sticks with me the most was, right around the time I actually got my diagnosis. The— currently my wife but back then we were still dating—

Julie: Wasn't it like your first date?

Connor: It was pretty close— [laughs] I'd just moved back up to Illinois, so we were still trying to figure out the whole narcolepsy thing, not really sure what was— how it had an impact on the relationship kind of thing. So she got a— [laughs] she got a full dose of what all the sides of it could be, that night, that's for sure. She had actually dropped me off from a date. I think we had went to go see a movie or something, that night. And, you know, I was pretty tired afterwards, I remember sitting down, and for a lot of these like hallucinations for me they tend to happen as I'm falling asleep, rather than waking up. And they're always— I can always tell it's going to be rough because I get a, uh— almost like you go over a hill too fast, you almost like lose your

stomach, kind of feeling. So, I sat down and this wasn't my first rodeo, but uh— it was definitely a more memorable one. As I'm sitting there on the couch I had the feeling of my, you know my stomach leaving me. And I remember my head kind of, feeling my head slump forward, and not really being able to move which initially startled me. But quickly afterwards I started hearing um— feet running through the house. Like bare feet on a wooden floor. Which was weird because I was the only person in the house at the time. Pretty late at night, I'd say probably close to 10, 11 o'clock. Only one in the house, but I kept hearing these feet running across the floor. I of course tried to move, get up— nothing was responding, nothing was working. So, I am convinced that there's someone in the house with me. Those feet quickly run into the kitchen, all this is happening behind my head, I can't see anything, I can only hear the feet running around. Feet quickly turn into things breaking and doors slamming in the kitchen, and I'm trying to call out, get up, grab my phone, just anything. 'Cause I can see— I can see everything going on around me, but like I said, I can't— can't move. Just stuck there, on the couch. Well, I have a moment of peace, as if I want to call it that, because the banging and the breaking and the feet running around stop for a moment. What winds up happening after all the running around in the house, there's this voice of like, this almost sounds like a little girl that starts laughing, behind my head. Of course I can't— I'm trying to turn to the side and look, trying to move but I can't, you know, just— I can't even call out for help at this point. And it feels like that goes on for forever. A— [laughs] a long time. And the laughing ends up turning into, a— I don't know if you, if anyone has seen any of the like, horror movies where you've got the uh— exorcism type of thing, and they start talking in— different language, real fast and like— almost like multiple voices at once, kind of thing. Can't understand a word that it's saying but that little girl is no longer laughing, she's doing that, behind my head. And that goes on what feels like forever. So, at some point during this you know, thankfully, I don't remember doing this but I was able to call my girlfriend at the time, my wife now— and she said that she heard me just muttering like, "help, help, help," over and over and over again. And she had managed to get all the way home which was about half an hour away from where I was, and all the way back to me, during this entire time. So that uh, that episode went on for at least an hour, thinking back on it now. Where I had the mysterious little girl whispering and laughing and running around through the house and me stuck on the couch.

Julie: So scary. Has she ever returned, or?

Connor: To that extreme extent, no. But the— you know she, uh— the running around, the feet running around on the floor that, uh— that happens on a fairly regular basis, and it gives me a nice little flashback— [laughing] every time— every time it happens.

Julie: I feel like they're often, uh— why are they so noisy? Why are they always banging around in the kitchen, and— [laughs]

Connor: Well they've got to let you know they're there.

Julie: [laughing] Yeah, exactly. Well thank you for sharing that Connor. Let's see, Krystin, did you want to share a little bit about your hypnagogic hallucinations and sleep paralysis experiences?

Kristyn: Yes. This one isn't as scary, although I have had some like— terrifying ones. But, I think this was when I was just trying to get diagnosed, so I didn't have a diagnosis yet but I was

pretty convinced that I had narcolepsy, and I had started a new job and I'm a news producer so I worked overnight, which means that I can work at like 10 o'clock at night, and I got off at seven or eight in the morning. And, most people would be very sleepy, I was trying to figure out if I had narcolepsy, I was extra sleepy at that time. And everyone in the office had already begun talking about the girl that's falling asleep all the time. I didn't know this yet but they had been telling my managers like, she sleeps, when no one's here— and so I didn't realize that I was falling asleep. I knew that— sometimes I knew I was falling asleep, I didn't realize I was falling asleep as much as I did. And so, I later learned that— we had really high ceilings, kind of like— I don't know if you've ever been to an airport, one time I was like in LaGuardia and the ceilings were super high and there were birds flying around, in LaGuardia. And I was seeing— I thought birds had gotten into the news room, and were flying around. And I kept being like, "Yo, that bird," it was like three in the morning and I'm like, "Ya'll don't see that bird? Like flying around in here?" and I'm sure they thought, there's something wrong with this girl, she sleeps, she's new, she's seeing birds— and I was just convinced that I— could see the bird, but nobody else could see the bird. And I didn't think that— I didn't think anything was wrong with me, I was just like, the bird is really fast, and it's really good at flying, and I'm the only person who can see it. And so that went on for like a couple of days like I would see the bird flying by, and I thought that it would like, it was getting in and getting out somehow. I later learned through Project Sleep because my sleep specialist did not explain what hallucinations were, that was a hallucination and that's what helped me to realize that, there are times when I don't realize that I'm falling asleep. That I am going to sleep in public, and as Julie was saying like, everything around me looks exactly the same, and so sometimes when I'm at work, something will happen and it'll be a normal day like I'll be writing, I think I'm writing a story— and then like, I don't know, like two knives will go across my— this computer screen. And they won't like hit me or anything, but— and then I'll be like oh! There are not knives in here, Krystin, you are asleep. And that's how I realize that, oh I should get up, and like move around, because I've been sleeping. And then when I like, especially if I'm starting to have sleep paralysis in that moment I'm trying to like wake myself up I'll like get this dream and like, I've written just gibberish and that's how I realize that I have been asleep but I would not— they're not always scary— the knives are scary. But— [laughs] they're not always scary they're just— abnormal— but only a little bit, to the point where you're not really sure if it's real and if I'm sitting straight up and at my desk I would not know. It's— it was not abnormal to me that a bird would get into a place with high ceilings, so I just thought that that was real. But clearly I was asleep.

Julie: Yeah, the very real, very real nature of these is incredible. I like to describe to people that, I just don't know if anything that happened around my sleep time was real or not. I pretty much assume it's not real— [laughing] because that seems like the first, best guess. [laughs] Yeah, well thank you for sharing. Um, Chelsea you want to share a little bit about your experience?

Chelsea: Sure. Like you had said about not being a stranger to nightmares or crazy dreams or whatever, I've been plagued with like horrific nightmares, for as long as I could remember. My mom said I was probably like two or three when they started. And so I've just dealt with them my whole life and you know during emotional times like if I was going through a break up or was stressed out about school or something they usually were worse, and that's true with every symptom of narcolepsy now I've learned, that it's— I'm stressed or going through a hard time makes everything worse, including my hallucinations— [laughs] but the first hallucination I can actually remember was when— right before I got diagnosed, living in Japan— but I—

Julie: Why were you in Japan?

Chelsea: So my husband was in the Airforce, he's retired now. He was active-duty Airforce and we were stationed in Okinawa, and I loved it there. And I worked with a lot of local nationals and hung out with a lot of local nationals, um so I got a real good experience and sense of the culture, which I'm sure also like, influenced the way I perceived these hallucinations because I— literally thought they were hauntings, like I didn't think I was dreaming, I thought they were for sure real. And I was being haunted by spirits, or something. [laughs] Which, because part of their culture is they believe that you're like surrounded, you know, by spirits and stuff, not necessarily hauntings all the time, but— we were living on base which, also, there was a lot of like, battles during World War Two in Okinawa, and especially in certain areas of the base, so there's a lot of talk about different houses that were haunted. So I'm sure that had a play on it as well but one night I was asleep and I— when I have a hallucinations I have them both falling asleep and waking up, I get them on both ends, unfortunately, and they're almost always coupled with sleep paralysis— so kind of like what Connor was explaining, like he couldn't move, he couldn't cry out, he couldn't do anything, that's what I experience as well. And the first one like it didn't seem horrific, at first— [laughing] so I was laying down and— no that's not true, it was. I thought I heard someone breaking in. To our house. And like I thought I heard glass breaking and someone like shuffling through things, throwing things around— yeah they're really noisy— [laughs] always. And, like coming up the stairs. I could hear someone coming up the stairs to our bedroom. And I'm thinking like, "Oh my god, oh my god, someone's breaking into the house." Someone's breaking into the house, like why is my husband not waking up. And I can't move or like scream out or call out to him or anything, and then all the sudden like it got quiet? And then, and my husband and I were like, like I was facing the wall, he was facing me, um— as we were sleeping on our sides. And— that's how we fell asleep. And I could feel him stroking my hair. The back of my hair. And like probably to calm me 'cause he could sense my distress and I thought, "Oh my god that is so sweet, that is so nice." And so I rolled over to like, thank him, and he was dead asleep facing the other direction. But I had physically felt somebody stroking— [laughs] my hair. And I thought like, this is unbelievable! So, naturally it was a ghost, right? That was stroking my hair— [laughing] so, this stuff happened all the time. I would feel things like, smack me, and I would wake up— I could still feel the sting on my skin. I had instances— and some of them were okay and kind of like, fun, like— my dad when we were kids used to pull our toe, it was usually our big toe he would come up and pull on it to wake us up, not hard just a little tug on our toe— and I had that, I've had that so many times. Like I can feel the sensation of him tugging on my toe, and I'm thinking, what's my dad doing in my bed in Japan? and I'm an adult and I'm married [laughing] you know and then you wake up, nope! Not there. And yeah, and so I remember like telling my husband this and he's thinking, my god, she's losing her mind. You know— [laughing] what's going on. I'm telling people I work with and they're like, "Ohhhhh. Your house is haunted, you should do this, you should do that." To get rid of these spirits, you know. Yeah. And then when I finally went to a doctor, to talk to a doctor which I went because I started experiencing cataplexy, which is what led me to see him, you know— he's like, well tell me about your sleep and I'm like, you want to know about my sleep? And I thought for sure if I told him, you know, he would think I was crazy! Because I knew they were real experiences, like I had real sensations with them. They were so different than dreams.

Julie: And what did he say? Didn't he say something about—

Chelsea: Oh. Well he said— well he— so, when I got diagnosed, so I ended up having to go off base to a Japanese doctor and a Japanese clinic, and not a military one to get the actual diagnosis 'cause they didn't have the ability to do it on base. And actually like ironically narcolepsy is much more prevalent in Japanese than it is in Americans. They carry the HLA at a

higher percentage so there's much more people like per capita in Japan with narcolepsy, than in America, so I guess I was in a great place for it, you know, to get diagnosed. The doctor asked me you know he said, he was this older, very traditional Japanese doctor and he said, "What did you think was happening to you?" and I said, "I thought my house was haunted," and he said, "Old way of thinking." [laughing] I was like— Okay, [laughing] touché.

Julie: I'm curious from Kristyn and Connor too, did you guys think of these as like, a medical problem? That you addressed with a doctor or more of like a— I don't know what's happening? Did you guys bring them up right away to doctors?

Kristyn: I never did. And I can remember an early one, it's honestly now that I'm thinking about it, that actually shifts my like timetable of when I thought I may have like, developed narcolepsy, I was like— I was a kid. And I thought maybe like, 14 is when— 'cause I can remember falling asleep in class, but I was like, 11, and I remember I was sleeping in my mom's room, because the night before I had felt really sick in the night and so I slept in my mom's bed that night. And then I remember, a— and I can draw it, like it's so vivid, which is why I believe it was my first one. And now that I think back I'm like, Kristyn why did you think this was real. It was like a snake but it had like no eyes, so it kind of was like a worm, and I was a kid so it was like a very child-like version of something. And it came up and bit my hand. And I woke up screaming and it still hurt, like I could— I can still feel it now, but I could feel it then. And, it's so crazy, you said did I ever talk to a doctor because the very next night, I had a seizure. It was just completely unrelated I was taking like medication as a child and— so my mom was staying, like three nights in a row I slept in her room, because the first night I didn't feel well, the second night I had the like bite thing and I woke her up and she was so afraid, and then the third night I had a seizure and I know I definitely didn't tell the doctor like, oh earlier the night before a snake bit me in a dream— I just thought that I was having a bad dream. And I honestly thought that like, the bad dream was like some sort of sign that I needed to stay in my mom's room. She would not have known that I had the seizure if I stayed in my own room the night before, but I— I was 11. So maybe, that was my first hallucination. And I definitely didn't tell the doctor about it.

Julie: Wow.

Chelsea: It changed my time table a lot too, actually— as I was preparing to do this, um, Nerd Alert. I was thinking about the dreams I've had and different things I've experienced and I'm like, you know, I can recall having auditory hallucinations— years before. So— but I didn't have cataplexy or any of the other stuff. And it definitely got much worse. But it definitely shifted my timetable too, so that's really interesting.

Connor: Yeah, to be honest, the— certain things that happen pretty regularly with me still, like the— call him the Shadowman— this someone that I see out of the corner of my eye, or— you know down at the end of the hallway whenever I'm just like— at the hospital it's really freaky. 'Cause I— [laughs] I work nights so I always, my heart jumps a little bit 'cause I'm thinking someone's out of the room that shouldn't be moving around. [laughing] Um— the Shadowman, I'd say I probably have been seeing him since I was like, eight years old. Yeah. That was— Yeah, I was right around eight years old, it was probably the first time. But, you know, like— like everyone else is saying, I didn't necessarily have all the other symptoms with it, I just kind of attributed it to really bad dreams and then uh— when they got really bad, to where like— I knew that I was awake, like I— there was— it wasn't a— oh I'm asleep and I'm dreaming, or I could pass it off as a dream— I was 100% certain that I was awake when these things were

happening, I was living in Louisiana and I'm a little— I wouldn't say superstitious, but uh— I was thinking like some voodoo stuff was going on— [laughing] down there, so I didn't want to sound, uh— crazy, to anybody— [laughing] but uh— when it followed me back up here to Illinois, I kind of had an idea that like oh, I'm kind of meeting all the you know, did the good old WebMD self-diagnosis thing, and uh— it kind of was like, oh I might have narcolepsy and that's when I started like reading about the— the sleep paralysis and the hypnogogic hallucinations, so. I didn't want— I still don't want to talk— you know, being a nurse you know it's like oh, it's fine to talk about these things but, even still to this day it's not something that I would bring up to the doctor, just 'cause it's— you know, you're scared of what someone might think, kind of thing. But you know, like Chelsea said, that's an old way of thinking.

Chelsea: Yeah. But I do think there are doctors who just aren't familiar with it. And if we don't necessarily use the correct terminology, or describe it just right, that they would think that you know we're having hallucinations that don't have anything to do with a change in wakefulness. And that we're just having an actual hallucination. Because they seem like that, you know, and the change in wakefulness is, um— god, it's so— slight. It's so hard to describe and get a grasp of it because I mean when I— when I lived in New York, I was having— I had gone through a bad breakup, and I was having horrific nightmares. They were really impacting my life. Like, there were times where I would call into work because I had to go to work late because I had a night of nightmares— [laughs] and I was— I couldn't function. Like—

Julie: You mean the hypnogogic hallucinations or nightmares?

Chelsea: They were not hallucinations, they were nightmares. They were like, just horrific nightmares. Usually they involved me being sacrificed, like literally burned at the stake. And I mean really horrible like, violent— just horrific like, dreams. Nightmares. And I would wake up and I would just be— like I would— I felt like I lived through them, but I didn't have any physical sensations or sounds or anything like that, but— I was just exhausted. You know? And um— and I was shaken from them. So I started seeing a— I'm— [laughing] I looked it up and I wanted to specifically see a Jungian Psychoanalyst who did dream therapy. [laughs] And I don't even know what they would call that now because terminology changes all the time, but I found this woman who— that she specialized in that. And I saw her and went to her for— I mean, a couple of years, probably. Year and a half or so, and she helped me tremendously. And in the beginning she suggested, 'cause I liked to paint and create things, so she suggested that I started painting these horrific images from my dreams.

Julie: Oh yeah. Yeah.

Chelsea: So— Yeah.

Julie: Well we're going to get to that in a little bit!

Chelsea: Yeah, so I did! So, yeah— do you want me to stop there and we can talk about that—

Julie: Yeah, yeah, we'll get to that in a little bit. So just a little bit of history too because, you know, I think for each of us that has experienced something like this, you know, it feels like, so— out there, but it's— but people have been experiencing hypnogogic hallucinations and sleep paralysis for a very long time. It's been described for at least 2,000 years and across many

different cultures, and it's not just people with narcolepsy that experience this as well. Different studies will say different numbers from what I could tell. Somewhere between 8% to 30% of the general population has experienced things like this at some point in their life. For people with narcolepsy it's just much more— consistent, that we experience these. But even the word nightmare, that we now think of is, kind of like what Chelsea was describing, it's from the old English word, "mære" I guess, a malevolent figure who lies upon, and immobilizes or suffocates sleepers. So, really even that term first was really describing a hypnogogic sleep paralysis you know, kind of like that feeling like someone's on your chest. And that, you know, there's been many interpretations, we love as humans to interpret and find meaning from things, and so there's certainly you know tons of dream interpretation throughout time, but also for these specific experiences you know thought of as super unnatural causes— witches, old hags, ghosts, demons, vampires, aliens— we have a great article on Project Sleep's website that goes through some of these different examples, and how they can be hypnogogic hallucinations. I know my first hallucination is a man coming into my room and I remember him reaching out towards my neck, but I don't remember, I don't think he was like crushing on my neck, I just felt like he was about to strangle me— but have you guys had that sensation, of like, not being able to breathe, or— that something's on your chest?

Chelsea: Absolutely. A lot, actually. And I started having that in my like, mid-teens. And I had that a lot when I was going through a stressful period in high school. And I had it— yeah. It felt like there was this like, darkness and weight on top of me that was so heavy, and it was super hard to breathe, and I couldn't scream out, I couldn't do anything.

Connor: For me there was— I mean, this doesn't happen as much, anymore, thankfully. But uh— the times whenever I have those— there was a point in time where it was— nightly, and it was so bad that me and my wife, we weren't sure if we were going to be able to share a room together because— [laughs] I don't have the flight instinct where I wake up, you know, just scared or scream or— anything like that, I typically lash out whenever I have the— where someone's holding me down, or— you know trapping me kind of thing. I would wake up and I'd wake up swinging. Or— [laughs] we only laugh about it now, it's not really funny, but— [laughs] we laugh about it now, but back when I was— it was closer to whenever I was, I used to do MMA and boxing and stuff. And it was closer to whenever I'd just stopped. There were times where I'd come out of one of those and I'd— immediately put my wife in a submission hold. Just, out of pure— instinct, reflex— because of how realistic being restrained felt. I was 100% for sure that I was being attacked. To the point where like, just like I said, instinct took over, whenever I would come out of it.

Julie: Wow. And isn't your wife also— wasn't she also a fighter though? She had some fight in her?

Connor: Yeah, she's a— [laughing] she's hit, bit— um— [laughing] yeah, she's got her punches in too.

[Julie laughing]

[Connor laughing]

Julie: Good.

Connor: [laughing] But yeah no, she's— she's made sure I've snapped out of it pretty quick.

Julie: Oh, good.

Julie: So strategies for dealing with this! I think it's always really interesting— [laughing] to try and think about, how could we make them better? You know, it's tough. And you know, there are no— treatments that are specifically like FDA approved, to improve these. I'd say that some treatments might improve them but they're certainly not FDA approved and indicated, for reducing these things. So, in general, some strategies could be anxiety management, sleep routine, keeping a regular schedule— looking for patterns and emotional preparedness. Environmental triggers, even pets' behaviors— so, I know for myself, and many people talk about like getting their sense of reality from a pet— [laughs] and realizing what could be happening or not happening, based on that. And looking for creative outlets. One strategy that I've figured out, I guess it would be kind of like, emotional preparedness— is that I've realized that if I'm questioning whether I'm awake or not, like is this really happening? If I can think that in my head as I'm having one of these, then I try to remember that that means it's probably not happening. Because once I actually am awake, fully— I'm always like, oh this is reality. Like I don't really, once I'm really awake I'm like, oh yeah, this is awake. When I'm awake-awake, it's not a question about whether I'm awake. And so I think sometimes when I'm able to realize I'm questioning whether I'm awake, I probably am not.

Chelsea: Does that— I have a question, does that work for you?

Julie: Sometimes! A little bit.

Chelsea: That's awesome. I need to get there. I— I feel the same way, like if I am questioning whether this is reality or not, 100%, it's not reality. Like I never question if this is reality, when I'm awake. And alert. But for whatever reason I don't have the wherewithal to realize that if I'm questioning it, it's a dream. [laughs]

Julie: Yeah. [laughs] Yeah, well—

Chelsea: It would be different.

Julie: Yeah. I mean, you know and even the— the transition we talked a little bit about that but, that transition between a hallucination and then being in your environment, I had like a mini jar of mace and then you know after one hypnogogic hallucination, living in an apartment— I started walking around the apartment with the mace looking for the burglar, and like 10 or 15 minutes go by before, you know— and I'm walking around, in reality— looking for the burglar. And then remember, I've been diagnosed with narcolepsy now at that point for like, eight years. Like— oh. The intruder— oh, jeez, wow— probably the thing that happens to me all the time. But how do I end up with the mace walking around the apartment for, you know, 10 or 15 minutes before remembering that like, duh. It wasn't real. [laughs] So it certainly, you know, I don't know if I really have any exact solution. How about you guys? Do you have any strategies for coping with these?

Kristyn: I don't know if it's a coping strategy, or if it's just— I know that if I'm really tired, or exhausted, I'm going to have more hallucinations. I'm going to be more prone to having sleep paralysis. So like, if it's Wednesday and I've had this every night this week, I'm like okay. I need to do something different, even if I'm going to sleep on my normal time, I need to maybe try to get some more sleep and, try not to look at my phone— try to see what is like, emotionally triggering me. If I'm like super stressed about something, because it's not going to get any better, it's only going to get worse. And then, knowing that I have— the chance of having sleep paralysis, it scares me so much— I will not sleep. Which will then make me more tired. So, it's kind of a coping strategy that I have that's after the fact, I don't have a way to like, stop them, but I feel like I have a way to help slow them down— is to just try to be as rested as possible, if I'm noticing that like they're happening every night.

Chelsea: Yeah, it's a vicious cycle. I have felt the same way and I know that once I start having them I'm more likely to have more of them, and then it's terrifying and so you don't want to sleep. And being terrified and not sleeping actually increases the likelihood of it happening more and yeah, it's a vicious cycle.

Connor: I know for me, the— for me it's stuff that— it's kind of funny, but it's stuff that, you know, they tell everybody, oh do x,y and z to sleep better. Don't look at your phone for a couple hours. Turn the TV off like an hour or two before bed. Make sure you don't eat for a couple hours before you go to sleep. Just doing, like actually being on top of those things tend to help some. Like somewhat. It's not necessarily guaranteed but it does help somewhat, at least for me. As for when they happen though, like coping strategies, we found out that— [laughs] we actually found this out through— [laughs] through a smart alleck comment that I made to my wife one night, whenever I was coming out of one of the— [laughs] one of them. I was, you know, I woke up screaming and it was a bad— bad moment. And I was still half asleep, I'd taken Xyrem to help me, you know, sleep that night. And it was still kind of working, I don't tend to have a filter when that's working and I wake up with that in my system. She asked me, she's like, "Well what can I do? Can I help you?" [laughing] I said, "What are you going to do? You get scared of everything." [laughing] So she's like, "Well do you want me to get one of the dogs?" I was like, "Yeah, get Bella. I know Bella will actually protect me." Bella's my little 50 pound like, pit mix. And so whenever— it's kind of the go-to now, is whenever I wake up from an episode, a lot of the times it's kind of a cycle where I'll have one, I'll come back to for moments and then I'll— fall back into it. And just happens over and over and over again and it can happen for hours. But for some reason, whenever we get my little 50 pound pit in the bed with us, she kind of just like centers me, I guess. Like grounds me to reality. Thankfully, the dog entertains you know, entertains my— [laughing] my momentary uh, lapse of sanity— [laughing] and um, whenever— whenever you feel the need to sleep, for me especially if I fight it, I'm guaranteed. It's almost like a for sure, I'm going to have an episode, if I try and fight the exhaustion and the sleep.

Chelsea: I have a little tiny dog and she sleeps next to me and we're almost always touching— [laughing] she's against me in some way, or I have my hand on her, and if I have a hallucination— she would be barking her full head off, if someone was breaking into my house, or was in the room. And knowing that she's not responding to anything is helpful. And calms me enough to where either I can fall back asleep or wake up. And it has actually helped stop the loops of it, that's what I call them, just like Connor, to where it's like you just get stuck in this endless cycle of— of hallucinations, sleep, kind of awake, hallucinations, sleep, kind of awake, and it can last for hours otherwise.

Julie: I also would say I do avoid scary movies— [laughs] and stuff, I feel like I don't need any more— material, for my hallucinations than it already has— [laughing] so, that's something I do as well. So, Chelsea, you did mention a little bit about your art, and do you want to share a little bit more?

Chelsea: So, the therapist I saw in New York, she encouraged me to paint the scary things from my dreams and I did that for a while and it helped some, and then she actually taught me lucid dreaming techniques, which helped tremendously, so I stopped painting them and just used the lucid dreaming techniques. But, when I started having the hallucinations and the sleep paralysis, I guess because my level of sleep isn't deep enough to do lucid dreaming, I can't— I can't control those at all. I was back at this point to where I had no— mechanism— of, or a resource to use. And so I started painting the hallucinations. I went back to what I had done before, and it actually really started to help. Just by using it in a creative way, I take ownership of it and I can manipulate it into the way I want to, and really— it's mine to own, they're my hallucinations. They're coming from my brain to begin with. [laughs] So it's really just owning what I already own— and saying like, mm— you're not, I'm going to let you be a little less scary. And in doing this, it made them not nearly as scary and actually they became a lot more tactile, like— [laughing] than visual. So sometimes I will write a story about it or just talk about it like, the bugs— I for whatever reason can't seem to draw the bugs, so I will write like little short stories or something. Or even horrible poetry about, uh— like, bugs. I've had many hallucinations that are kind of like the, um— Indiana Jones, in the Temple of Doom, where you're just like, literally like covered with insects crawling all over you. So I'll write something about that and just using it in some creative outlet has seemed to help me.

Julie: Yeah. You know, you've got to look for the silver linings as we say, and— as best we can. Doesn't make these things go away but, all the creativity that comes from this is incredible. So we do have some poetry to share as well. From [Elizabeth Wilson](#). Elizabeth Wilson was diagnosed with narcolepsy type 1 when she was 38 years old and she's also a graduate of the Rising Voices program and an award winning poet. And she just actually published her first book called *Window Panes* and she has actually recorded a quick video of her reading her poem for us that we're really excited to share today.

Elizabeth Wilson on recording: Night fall. I'm electric. A current ripples from my crown to my toes. The ossicles in my ears hum and whirl. I'm restrained by a witch, stronger than gravity. Her incantations press against my chest, crush my breath, this is a dream, I tell myself. A nightmare, for the waking. If I can just move my pinky finger, I'll break her spell. I'll wake up. Night will fall around me.

Julie: So powerful. That just gave me chills.

Julie: Well if you guys can't get enough of this topic, I recommend this book, "[The Terror That Comes in the Night](#)". It's a really interesting book about looking at people's experiences in Newfoundland in Canada, in particular and he does go through and describe a lot of different history of a lot of different cultures, and— it was so validating to so many of my hypnogogic hallucination experience, and it brought more back to me, you know that I'd forgotten about. So reading this book, I think— I just looked at it again, I hadn't looked at it in years. and all the notes I'd put in the sides, I think I probably read this before I wrote my own book and a lot of the hallucinations that I ended up including— I felt very validated by hearing other peoples' very

similar experiences of— from this book, so. Definitely recommend that if you want to get more in to this topic. And we do have this great article on our website, about spooky nighttime visitors, paranormal or parasomnias by Rebeca Fluoco. So check that out as well, just in closing, just to remind everyone that there are great organizations that have great resources, including Project Sleep but also in America the [Hypersomnia Foundation](#), [Narcolepsy Network](#) and [Wake Up Narcolepsy](#) have various great, great, great resources and there are also international organizations around the world, we have a list of those on our [World Narcolepsy Day](#) page. And, you know, really interesting how different cultures interpret hypnogogic hallucinations and sleep paralysis as well. Chelsea talked about Japan, but you know some of our different speakers from different countries have talked about you know how things are interpreted in their countries, so a really interesting discussion there too. And just a quick reminder that we will have a toolkit coming out from this discussion. So with that, I just want to thank everyone for tuning in today, and a huge thanks to our special guests today for sharing with such vulnerability and honesty, I know this topic is— you know, it can be hard to talk about and it's hard to experience, so your willingness to come here and share just means so much. Because, you know, maybe we can't always make them go away but, there is a lot of power in knowing that we're not alone. Cheesy, I know, but— so true. Alright, thanks everybody!

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