Project Sleep Narcolepsy Nerd Alert Narcolepsy and Napping (Season 1, Episode 7) Transcribed by Mirela Starlight

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In today's episode, Julie talks with Dr. Ortiz and Mary Murray about their own individual experiences with napping, including whether they schedule their naps, where to nap at work or school, and the struggle between not wanting to miss out on life by napping with the fact that napping is also a form of treatment for those with narcolepsy, idiopathic hypersomnia or other sleep disorders.

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 and Napping" (Season 1, Episode 7) 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: Is napping an unwelcome symptom of narcolepsy, or a helpful treatment? In today's episode I speak with Dr. Luiz Ortiz and Mary Murray about how we can make space for naps in our busy lives. Especially in a culture where sleeping is seen as a form of laziness or weakness. Dr. Luiz Ortiz is a pediatric sleep specialist in St. Petersburg, Florida. Living with narcolepsy himself, Dr. Ortiz offers invaluable insights, from both a medical perspective and his firsthand lived experience. Mary Murray is a teacher and mother living with idiopathic hypersomnia in Los Angeles, CA. Mary is also a Rising Voices of Narcolepsy advocate, and her powerful essay, <u>Nap Roulette</u>, is published on our website.

Julie: I'm so excited to have you guys with us today. We're going to kind of break down the discussion, just so you know— to talk about before napping, during napping and after napping. I'm so excited about this 'cause I think they actually all deserve time and attention, for today's discussion. We just have a quote here from Dr. Macario Marleny, who was part of the wonderful <u>video</u> that Dr. Ortiz was also a part of, specifically talking about doctors with narcolepsy. And she had this beautiful quote, "Don't fight against sleep because sleep is always going to win." And I just love that and I hear that in my own head many days.

Dr. Ortiz: So, kind of what I learned during my training really hits home and, and I feel it's really important to share kind of what the process is as to why we want you to know, why your sleep doctor wants you to take a nap. And so this comes from decades of research on what sleep is, what its purpose is and how it works in our brain. Sleep is not one process. Sleep is actually two separate processes. You have one part of your brain that works towards making sleep, and another part of your brain that works towards keeping you awake. They are almost like diametrically opposed, and believe it or not, a lot of systems in your body work that way. It's not a gas— you push part of a gas, you go faster— it's more like, it's like a balance thing. And so when one end is stronger than the other, you get one action and when the other one is stronger on the other end you get the opposite action.

Dr. Ortiz: And so, with sleep and wake you have a process, called Process S, which is your sleep drive. And that gets stronger and stronger the longer you go without sleep. And then you have Process C, which is your circadian rhythm, which is also your wake drive. And unlike your sleep, this one waxes and wanes through the day, so. As you wake up it supposedly— starts to get stronger, stronger and then as the day ends it gets weaker and weaker. And your greatest urge to sleep is when the Process S overcomes your Process C. Now, with narcolepsy, it's not that the Process S gets stronger, it's more that the Process C just drops out— it loses it's intensity— at inopportune times. And so, instead of having the greatest urge to sleep occur at nighttime like normal, you'll have the greatest urge to sleep occur several times throughout the day because your Process C is just dropping, and then it comes back on.

Dr. Ortiz: And so the whole idea of taking a nap is to blunt the affect of Process S because – when you go to sleep, that process, that drive, just drops. And so, by taking a nap you drop that Process S and it makes the balance a little bit – better, for making sleep. And so in typical people, people without narcolepsy, napping has shown to improve alertness via diminishing that sleep drive. Studies on the effectiveness of nap in people without narcolepsy have shown that a short 15-20 minute nap can improve driving performance. The downside is, if you take a longer nap, you can have grogginess and not feeing good, and this is called sleep inertia. This typically occurs when you start to enter a deeper sleep. And when you're awoken from a deep sleep, you just don't feel good. And so to avoid that, you keep your naps short - if you start going beyond 20 minutes into the 30 or 40 minute mark, you start entering that deep sleep. When it comes to narcolepsy and napping, scheduled napping has been considered a standard care, a standard treatment for treatment of narcolepsy, regardless if you're on medications or not. It just blunts the effects of the sleep drive in making you sleepy and in improving your alertness. However, it is rather under utilized because of many social constraints, psychological constraints, and it's unfortunate 'cause it - it can work, and there have been a lot of studies that show that napping helps. Several studies have shown taking a series of 15-20 minute nap has shown to have the ability to stay awake at 4pm. They'd have people with narcolepsy take a nap and then they'd – they'd do like a, mini MSLT, they'd ask them - they'd try to see how long it takes them to fall asleep and there's definitely - it takes people with narcolepsy longer to fall asleep if they had previously taken a nap. Another study has shown that taking 3 regularly scheduled, 15 minute naps, each day, for about a month, not only does it decrease unintentional napping but it improves general daytime alertness. And ideally, you know a lot of these researchers continue saying that you should not have any long naps to prevent this deep sleep, to prevent the sleep inertia. You don't want to feel bad when you wake up. However, often times that still happens.

Dr. Ortiz: On the flip side, another study has shown that— they actually encourage— their results suggested taking actually a very long nap, a 1-2 hour nap or around 20% of however long you normally sleep at night, can be more effective. And these authors, they had people take this 1-2 hour nap about 12 hours from their middle of their time of sleep. So, let's say you go to sleep at 10 p.m. and you wake up at six in the morning. So that middle of the night time

is 2 a.m., 12 hours from that is 2 p.m. So if 2 a.m. is the middle of the night of your sleep, these researchers had the person take a nap at 2 p.m. And by doing that, not only did it help with the reaction time of these people with narcolepsy, that they were able to process things faster, but they also found there was less unintentional napping. They also found that since you're getting that deep sleep, but you're sleeping so long, you're already out of the deep sleep by the time you're woken up— you don't have that sleep inertia, you feel better.

Dr. Ortiz: The other author still kind of recommended also taking a smaller nap in a day, however I found that this is kind of opposite of what a lot of people— what a lot of people without narcolepsy are told, that— to take that power nap. And so I found that it's really interesting, and so if you think that the short naps aren't working for you because you just feel so bad, maybe you should just take one big long nap in the afternoon.

Dr. Ortiz: Additional factors to consider, one study that looked at people without narcolepsy, that if they drank 1-2 cups of coffee and then take a nap, they were more alert. And this was in drowsy drivers, but I feel like that it can still be applied here. So the caffeine in coffee boosts your wake promoting drive, and then that nap decreases your sleep promoting drive and so that you, thats how you improve the alertness. To apply this into narcolepsy, so let's say we take an afternoon stimulant dose, try to schedule that so that you take your stimulant dose right before you take a nap, or at the same time that you take a nap so when you wake up you have the full effects of that stimulant at the same time that you're minimizing your sleep drive.

Dr. Ortiz: Of course any medication changes should always be talked with your own sleep physician. So I can't really recommend it specifically for you, but it's something to talk with your sleep doctor about. So I hope this was helpful in trying to explain why naps are important and why napping can help. And maybe this can lead up to further discussion with you and your sleep physician.

Julie: Thank you Dr. Ortiz! I just really appreciate you kind of going through that with us and bringing it — different research, together for us. That was really, really cool and I'm thinking, Mary, is this taught in science classes? It should be.

Mary: We definitely should be talking about it more in science class. I talk about it in health class a lot, especially with students who get tired during class. And I always try to engage them in conversation, especially if they've started to kind of doze off, 'cause they expect to be— in trouble, almost. And I'm like, you're not in trouble, let me tell you about some stuff! So yeah, I should— maybe I should steal a copy of that from you to present in my health classes.

Dr. Ortiz: That's interesting that you say that the kids feel like they're in trouble. When parents bring their kids to me 'cause they're excessively sleepy, regardless if it's like, narcolepsy, IH or sleep apnea— you know a lot of times if they're falling asleep the kids do feel like they're in trouble, and especially younger kids they feel like they're in trouble because of that. And I think that's part of the reason why there is a stigma against napping. People are told at a young age that falling asleep is not a good thing. Especially in public, or in certain situations and I feel that that's kind of hurting everyone, especially when— even people without narcolepsy could benefit from naps. There's research that shows that taking a power nap can help your function in the afternoon if you don't have narcolepsy. And I think the problem kind of starts even before people get diagnosed with narcolepsy, or even have narcolepsy.

Julie: Mm-hmm. We find that for our Rising Voices of Narcolepsy advocates, a few of them had in their story about how they went to truancy court because of missing school, because of sleeping. It really struck me, after you've heard it a few times, and you think, so you made it in front of a judge before you ever made it in front of a doctor— for your sleepiness. And like that

breaks my heart that that's, kind of how – getting in trouble for sleeping, before anyone considers medical.

Dr. Ortiz: Mm-hmm. Yeah. I feel like teachers are really important in trying to recognize these issues. I'm starting to get more like, the parents are telling me like, the teachers are telling me that they're concerned about whats going on and— isn't your child getting enough sleep or not? They don't think that, I'm hearing more that like the teachers are more concerned about the health of the child rather than the child is being bad or misbehaving and, and so that's— it's good, that there might be a change, but I think— education for teachers 'cause they're, they see the kid every day. And sometimes they see the kids, more often than the parents. I'm glad that Mary's a teacher and she's helping out that way too.

Mary: Oh yeah. For sure. Thank you! That's actually really good to hear that you're hearing that happening more often. Because I try to make sure that when I see kids who are sleepy or napping in class, I always check in with them, I never— I don't know, it's just interesting that their default is, "Oh I'm in trouble, I was sleeping in class. I'm so sorry, it won't happen again." I'm like, "But are you tired? Because if you're tired, that could be a slew of things— I'm not mad at you."

Julie: Let's go into our discussion about before napping. We had— one of our speakers, Anne Claude, from Montreal— she had this beautiful description about, how when she started to feel tired, I think her natural inclination and how she said it was, her inclination was to turn up— instead of turn down. Kind of like you think of like turning up your energy, and she said that her husband helped her, when she was sleepy to move towards turning down her energy. But I wondered, would that— sometimes I can't tell whether I'm just having a small energy dip or a big energy dip. And I didn't know if that resonated with other people— and our special guests today. Especially if I'm about to go do something. So there was one day I was about to leave to walk to Starbucks and do some work there, and right before I left, you know, I thought mmm, is this a little dip or a big dip? 'Cause I would be away for a few hours and not want to sleep at Starbucks, I'd just rather sleep at home. And so, I don't know if anyone else has like, tips for how they figure out whether they should try to push through, or turn down— and should we fight sleep or— or, welcome it? So, do you guys have any thoughts about that?

Dr. Ortiz: I'm still trying to figure that out myself. I often tell myself you know, if I was a smart man, I'd take a nap right now, and — and then I still truck along and — I end up wasting more time if I say, if I try to fight it. My work is not as good. It takes longer for me to do it. Whereas if I took a 15-20 minute nap, or even an hour nap, I wake up feeling better and I can get so much more done and it's just — you know that brain fog really limits your ability to make a good call sometimes and — you know sometimes you're lucky and it kind of clears up after 10 or 15 minutes, and — other times, yeah you're still stuck in that fog and have a bad day if you don't take a nap.

Mary: I'm— completely agree with that sentiment. I try to tell myself when I am turning down I guess, that it's— it's an investment in my future self for that day. Like, I'm laying down, I'm closing my eyes so that I can— do more later, because it's really hard sometimes for me to slow down— 'cause I have so much that I want to do. I have work to do, I have things I'd like to do, I want to, you know, read that next book and play with the kids, and— cram everything in all the time, and— I'm really working on trying to be okay with stopping and taking the nap before it totally takes me over and then it turns from a 15 minute nap to a two hour, I still can't get out of bed because I'm so beat, sort of situation.

Julie: Yeah. I don't know if it is something, I feel like I can sometimes sense is that I get achey in my shoulders, and I've learned that is an early sign. When I found the word FOMO I was like,

oh my gosh, this is so much I think. I just want to kind of like, at least say, that— the hard part about napping is, that it takes time! Like, it does take time. Even if it is just 20 minutes, if you know— when you look at kind of like the impact of the condition, taking 20-40 minutes or an hour out of the day when you have 12 hours is still, kind of a lot.

Dr. Ortiz: Yeah I was just thinking about this, it's like I think people with chronic diseases, they have an idealized life of what would things be like if they didn't have that disease and I think that perception is always going to be a lot better than what it would've been. And so, I just think about too, a story that was told to me when I was in medical school about people who have had concussions – and how they rate their ability to think, process things, headaches, you know, like - their quality of lives. They compared it like, how their lives were before and after the concussion and then - they compared that to people who'd never had concussion. And basically, people with concussions quality of life were like, some of the metrics, like how well they process things, how many bad days they've had – it's pretty similar to people who've never had concussions. And really what people imagined their lives were before that concussion, was- too, too perfect- too idealized, not consistent with real life. And I feel like the same thing is true with narcolepsy and idiopathic hypersomnia. You want to believe that if you didn't have narcolepsy you'd be able to get all this stuff done, and — that may not be true. And - yeah, maybe you could get some more stuff, but - it's not so much and then we end up pushing ourselves to do more. And that includes missing naps, not taking the naps, and pushing ourselves to do more than we really should and then we end up feeling worse the next day or the day after.

Mary: I think that plays into why I've started telling myself that like, it's an investment in my future self.

Dr. Ortiz: Mm-hmm.

Mary: Because I will try to push through sometimes, especially if there's something that I really want to do, or somewhere I really want to go. But then I know that even the next day or the day after, they're just going to be ruined. Like, I will ruin it for myself and not be able to do x,y,z and I'm really working hard on accepting the fact that I do need to take these naps, and doing that will allow me to not have FOMO later.

Julie: Scheduled or un-scheduled? So. I don't schedule my naps. I probably should but I just tend to feel that sleepiness kind of comes when it comes and I— I do find that it's early evening, for the most part. And of course it'd be good if I'm on a really routine schedule, that that would probably help me to kind of nail down a time but, I was curious if you guys schedule your naps?

Mary: I don't schedule my naps, as you probably famously know, Julie, because I refer to my napping as nap roulette. It's like is it going to be 20 minutes, is it going to be two hours, I don't know— I just take it when it comes, if I'm in a situation where I can take a nap. Like if I'm teaching, and I'm feeling really sleepy, then I have to kind of push through that until I don't have students in my classroom anymore. But when I'm at home, generally I don't schedule my nap. I know like, I look at my day and I think to myself, okay— when is there a time that I will be able to nap, when will it be when I can like, miss out on the least amount of things, or have the least amount of responsibility. When we went back to school in April, after, you know— COVID shut down, I was teaching online for this whole time which was lovely because I had some longer breaks between classes, I could nap during the day, it was beautiful— that was about the best part of it, 'cause the rest of it wasn't so great, but— we were going back into school and I was going to have students in my class room— all day long. And I was not going to get a break from them. I was going to have to have somebody come and break me— to like, go to the

bathroom, for example. And I was really worried about napping. So at that point then I did start scheduling myself naps to get through the end of the school year. During lunchtime, just— so I knew that I had that time, and I really looked forward to it. I can see the positives of both sides, I think that you know, what works for people, works for people, but— for me like, it's like, oh I'm tired, I'm going to take a nap now.

Dr. Ortiz: So, yeah. I don't take scheduled naps either. I wish I could, because I feel that it would be more beneficial than waiting until I feel tired. It's just, yeah. It's just, things are busy—and—you have to wait for a lull in things. Or, I got to wait until I got—my work is being compromised by it, and I can't say no, and so I feel that—if I was able to schedule it, I— things would be better, if— or, I think after you know, reading all the stuff for napping I feel like I should make a bigger effort in, in scheduling my naps. Because, I mean the research shows that scheduled naps seem to be better. So that's kind of my new goal in terms of my self care—to schedule the naps.

Julie: Let's move on 'cause there's just so much. So here's kind of the quote I think that someone else had already quoted for us. "Take the nap before the nap takes you." Where to nap? Okay, like I just - logistics, okay. It's so tough, in a lot of different situations. And so, for me— it's been at workplaces, oh actually in law school too— I got an accommodation of a cubicle in the library basement, which was kind of away from - other people, so it was public but it was - somewhat private, I guess. And that cubicle is where I had a blanket and I would just put my head down and nap. I had a lot of hallucinations of people walking by me, [laughing] in that space, but. It is what it is. But then work has been tough, and so - in one job at City of Hope, a cancer research center, we moved from offices to an open floor plan situation. And our cars were far away, so it was really - kind of a hard situation, so we ended up creating two wellness rooms - and I kind of like that because I've heard some people say, you know, instead of talking about going to take a nap, they can even say something like, "Oh, I'm going to meditate." or something, you know. Or, um, do a little deep breathing, and that that can be more easily understood by people who do not have narcolepsy. It just had this kind of like, I don't know, leather looking bench, and a pillow. And then I would bring a little backpack with me where I had a blanket. And I would mostly I think put the blanket over the pillow 'cause I didn't actually want to put my head on the pillow itself. And, so yeah - and there was a lock on the door, that was important to me. Of course I still had hallucinations that people were coming in. But, you know. That just felt better to me. And Mary, do you want to describe you? From yesterday?

Mary: Yesterday! Yes! I found a lovely shaded nook, yesterday. We went to Disneyland. Which was wild because, it is Disneyland. It just feels so surreal. But anyways, it's exhausting. It's tiring, I'm sure for someone who— who doesn't have narcolepsy, who doesn't have IH. But, I knew that I was getting really sleepy and I was probably considering just like, sitting down and putting my head down somewhere, but— I found this lovely nook that was shaded, it was like kind of like a triangle situation, back in toon town. And I just curled up and I— I don't know how long I was asleep. Probably about 15-20 minutes. My husband was there and, he was watching the kiddos playing on the— like the play structure. But yeah, you know when you're doing— whatever— napping's important and for me now especially I know, when I need to take a nap, I need to take a nap. So I find that location where ever it may be, and I close my eyes and— sleep. When my daughter was a lot younger, like, I don't know, six, seven years ago— I absolutely sat in her stroller and napped. Before my diagnosis. I think there's some photos of that floating around somewhere. You know, you got to take that nap. Where ever.

Dr. Ortiz: I take naps in my office. I have a little pillow I keep in my desk. It's like in a big drawer, typically for files, and I just take it out and I just like, sleep on the floor. Put a little sign that says—

Mary: I've done that.

Dr. Ortiz: – "do not enter, do not knock." And uh, I take my nap.

Mary: I've done that at work too. If I don't have any students, same thing. I have the same kind of pillow, and I put it on the floor, and I would zonk out. Same thing. [laughs]

Julie: And I think it's a pretty reasonable accommodation, I don't really want to get into like, legal stuff, but— I remember my dad saying— he was an employment lawyer and he always said that, you know making an accommodation for someone to nap isn't that expensive. So it really shouldn't be too problematic for a workplace to find somewhere. But, just something to keep in mind.

Julie: During napping. You know, I just thought we could take a second to talk about it, because I think the experience is, also, itself — an interesting one. And sometimes when people say things like, you're so lucky you get to nap. Or, oh like, that sounds so wonderful. You know, like I went to the spa, got my nails done. And so, how do you feel during a nap? I know for me, it can feel quite busy. It can feel like I didn't nap at all. Like I think that I'm still awake. And other times, the hallucinations. Possibly the drive towards REM sleep in particular, and that our brains might want to go into REM. I don't know, Dr. Ortiz, if that — theory, checks out. But that experience to me feels quite active sometimes.

Dr. Ortiz: Yeah, I mean, vivid dreams are — a key feature of narcolepsy. And so the, you know often like, before I was diagnosed I would fall asleep in, in class, and — I dreamt I was still awake taking notes, um, you know. So just having vivid dreams, that can really just make you feel like you never took a nap at all 'cause it just, feels indistinguishable from waking life.

Julie: Mary, how are yours? Do you feel like they're quite active, or -?

Mary: Yes. Everything that you just said about your naps, could describe my naps. I often feel like I haven't been sleeping at all. I'm very confused then when I wake back up, I'm like, *ah*, *I mean to take a nap.* And I just feel like I didn't. So, they're not— always entirely restful— sometimes I feel like it's taking me forever to fall asleep when in reality I probably fell asleep right away and I just don't feel like I have napped at all. And, Dr. Ortiz, that's funny you say that about the being in school, because I had a dream one time that I taught a full day, like went to work, taught a full day— I mean totally mundane, regular kind of stuff— and then upon waking I realized that I was now waking up, to do the exact same thing. And I'm like, *you've got to be kidding me.* Um, but yeah—

Dr. Ortiz: [laughs] When I was like 10 years old I think I went through fourth for like a hundred years— 'cause it was like, every other night I dreamt I went to school, and—

Mary: Ugh!

Julie: Oh, man! At least the dreams can be fun, guys - I mean, like -

Dr. Ortiz: No, my — my dreams are super boring. They're, they're — pretty much, work or school. And sometimes like if I don't plan to nap, I'm like, *wait did I fall asleep? I feel better now. Did I fall asleep with my eyes,* like — like 'cause I'll try to work and all the sudden like, the fog is lifting, and it's like — *I fell asleep.*

Julie: Which is the perfect segue way to after napping.

Julie: I'm sorry to quote myself, but I couldn't find something quickly that gets at this, which is - "While napping I may look like sleeping beauty, but waking up I'm never guite sure who I'll be: a kind, calm beauty or an angry beast." So, I think actually it was through having a three year relationship where we lived together for three years that I learned about this side of me, and I've heard this echo with a lot of parents of kids with narcolepsy that waking up can not always be- such a- clear experience, it can be quite confusing, and sometimes, what happened with my boyfriend at the time, would be that I would wake up, and then I'd jump on him about something. I even convinced him once that he was wrong about something – and then later I was like, that was so not a big deal and I – and I don't – I can't believe I, I tried to get angry with you about that. And so — what we ended up doing was setting a rule, well, kind of, you know, a rule, or just a guideline that — the first 30 minutes after I woke up, we didn't speak. We just kind of walked around each other in the apartment and did our own thing. It wasn't like we were mad at each other, we just kind of did our own thing. Until I could feel like, okay. I think I'm myself. So that's how I've kind of handled that, and I don't know if you guys have personally experienced any sort of, coming out of your naps, sometimes feeling - not quite yourself?

Mary: You know, I think for me, when I am waking up if I don't feel like myself, if I feel — angry, or sometimes foggier than I was before I even started taking the nap, I legitimately just try to close my eyes and go back to sleep. As like a reset. If I can. Because sometimes I don't wake up feeling very refreshed or I don't wake up feeling very much like I've taken a nap. And I can tell that, usually because things feel loud — I don't know if that makes any sense, but like everything seems really loud to me, if I'm waking up and not quite ready to be up. And I get bothered by the slightest of sounds, at all. So I'll like wake up and come out of the bedroom and, you know maybe my family's watching television or something or talking and I'm just like shushing everyone and turning things down and I'm like — eeeh, okay, maybe I need to try again. And I will legitimately go back into the bedroom, lay back down again and try again, so that I don't have that feeling.

Dr. Ortiz: Yeah sometimes I wake up and I just feel like — ah, jeez, I feel — bad — and I just decide to go back to sleep. But oftentimes, I wake up feeling great! And I just don't care about anything, and I'm like, I don't even get my day started until like maybe an hour later, or two, like — But the other part of me is like, what are you doing, we got to do this, this and this! And I'm like, eh — okay. And, go back to — looking at my phone, or — you know, wandering around the apartment. By the time like eight o'clock or nine o'clock it's like, something shifts. I'm like, oh. Got to get to work, got to get this, got to get that done. And like, I — my brain shifts gears. It's almost as if, part of me is still asleep and even though I feel good, it's just like my — motivation is — kind of still asleep.

Julie: That really resonates with me. And, and — just kind of, going with it. Maybe, you know, and just like riding the waves. I know for me, just as a person I think I go on waves of motivation, in general. More like weeks and not like, exactly times of the day, but — just kind of riding that — you know — where ever your head is.

Dr. Ortiz: Mm-hmm. I think that's important, just not to try to— not to fight too much. It's like, guide it, but don't fight it.

Julie: Yeah. And I know that, Dr. Ortiz, I don't know if you have parents that talk about their kids not waking up in— not good moods at all.

Dr. Ortiz: Well, it depends. I definitely have— it's like a spectrum, I have kids that have the very classical narcolepsy pattern where they wake up great, no problem— soon as they get to school an hour or two later, they're— they're asleep. And they may do funny things like around their sleep, or— sometimes it's like they wake up, they say okay, I'm getting ready and then as soon as the parent turns their back on them the kids back to sleep. But they're totally fine with awake, and then I have other people where it's like, I wake up feeling awful, I feel bad— and then maybe it's like, not until an hour later where I feel like I'm myself— and then I, I feel kind of tired and then I take a nap, and then the afternoon I feel the most awake, I feel like my most real self during this time of day. And then it just starts all over again, once I go to sleep.

Julie: Well I just had this quote and you can— if you're, uh, you know you can say, you know, he, her, them— "Let them sleep, for when they wake, they will move mountains!" And I just love that and I try to, I know it's usually a little baby— for a baby's room— but I have it, and I love it. And I just think that's kind of a nice reminder to myself.

Julie: Well, um— do you guys have any— closing thoughts, or— anything you feel like you didn't get to say, that you'd like to add to this important discussion?

Dr. Ortiz: You know, I feel that a lot of people feel that they can't take naps because of their certain situation and — and I really encourage people to kind of, every time you tell your doctor that, or your loved one that, when they suggest it like, take a look. See— is that really true? Is it more that you're trying to reach that goal that you feel that you're going to be missing out on? Or is there a way, and often times I feel like, at least when I'm talking with some of my teenage patients, that— you're going to miss out with hanging out with some of your friends for an extra half hour, but I think in the end it— it's going to make you feel better. And I feel that's the same true with— for a lot of people. And I even deal with that problem myself, and I feel that we all just got to be honest with ourselves and, just realize that— this is part of the way that we live our best lives. Greatness doesn't happen randomly or, like, unexpectedly. Athletes have to train hard and they have to do all their kind of, consistent routine and schedule. The same thing, you know nothing exciting is going to happen, because— you know, you're not going to miss something exciting, because you— you took a nap, you're going to be having a more interesting and varied life, if you do take a nap. You're going to appreciate it more. Versus, staying up and— kind of living in a fog.

Julie: Which could be – your quote about greatness makes me think, why aren't we having some sort of nap olympics.

Mary: I would so be into that. I'm - excellent at sleeping. Let's do it.

Julie: I don't even know what that quite means yet, but I just think we got to do something.

Mary: I was just going to, you know, add that— I feel like I spent a lot of my life almost being embarrassed about the fact that I really needed to take a nap. And I definitely used to sleep a lot more than I do now, before treatment. But, accepting the fact that naps are part of that treatment as well, and not being afraid to let people know that that is what I'm doing, has been really helpful for me. Because when I was younger and before my diagnosis, when I would say something like, I really need to take a nap— I would get a lot of, um, side eye— a lot of people looking at me kind of weird, like, you're too old to take a nap. What are you doing? I came home from college one time and I told my sister it was my nap time and she was like, what is wrong with you? Not— I'm just tired, and I need to take a nap! So I've really been trying to own that lately, as an adult. And letting other people know that it's okay, too. You know, so diagnosed, undiagnosed. If you need a nap, take a nap. And, it's okay to tell people that that's what you're doing. So I've been trying to tell people that now, because— I think there's a lot of

stigma about it. But as you can see from everything that we've just discussed, it's really important, and it's a valid treatment.

Julie: Well said words, my dear. [laughs] So, thank you guys so much for tuning in today. This has been awesome. Thank you to our special guests for joining us. I'm just— always inspired to hear other people, sharing about this topic, and— hoping that we can always do better, but also not be too hard on ourselves if we're not perfect. And— we'll hope to see you again soon! So, thanks again everybody!

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