#### Sawbones 142: Narcolepsy

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[theme music plays]

#### Justin:

Hello everybody and welcome to Sawbones, a marital tour of misguided medicine. I'm your co-host, Justin McElroy.

## Sydnee:

And I'm Sydnee McElroy.

#### Justin:

Well, this is kind of late recording session for us. Normally we don't record this late, both in the week and the evening, specifically.

#### Sydnee:

No, no. That, that is very true. We, you know, I used to be quite the night  $\mathsf{owl}-$ 

#### Justin:

Yeah.

#### Sydnee:

... in my younger days and so this would be no big deal for me. Uh, but, you know, I don't know if it was turning 30 or having a baby.

#### Justin:

Or a little bit of both.

## Sydnee:

Or both. But, uh-

#### Justin:

Let's not pretend. That is not fake, people. That's the real stuff.

So, now you know you're in for a really good show.

## Justin:

No, that's the one I do. And now I'm drinking some, uh, Diet Coke, with a whiskey. And, uh—

## Sydnee:

[laughs]

#### Justin:

... spicing, spicing things up a bit.

#### Sydnee:

So-

## Justin:

Our daughter is done sleeping. She's over that phase, the sleep phase.

#### Sydnee:

She, she actually, this is true. I haven't told you this yet, Justin. Tonight, Justin and I take turns going in the room and trying to coax her into sleeping for as long as that takes.

## Justin:

You know-

## Sydnee:

We just keep trading off-

## Justin:

... upwards of an hour.

## Sydnee:

... tagging in and out as we get exhausted.

## Justin:

Yeah.

And, uh, at one point I had her in her bed, curled up with her baby Margaret, her favorite stuffed animal and her blankie, and she was, I thought, drifting and she sat up, pulled off her blanket and looked at me and said, "I'm done."

## Justin:

[laughs]

## Sydnee:

And I said, "What?" And she said, "I'm finished."

#### Justin:

Great.

# Sydnee:

"With sleep."

## Justin:

Yeah.

#### Sydnee:

"With sleep."

## Justin:

With sleep, forever. And it's so ironic because the thing about it is, it's like a, maybe this is what people mean when they talk about the generation gap. I would give anything—

## Sydnee:

[laughs]

## Justin:

... for two giants [laughing] to come put me in my bed and insist that I go to sleep.

## Sydnee:

Her bed looks so inviting too. Her big girl bed, her toddler— I don't know why—

## Justin:

It just looks-

Maybe it's just because I miss—I miss sleep.

#### Justin:

It's dark. I miss sleep, and Sydnee's been on-

#### Sydnee:

It's dark. The bed looks comfy.

#### Justin:

Hospital service this week, so she's up at 6:00. Anyway, this, this, we're just sleepy is the point, and we're sleepy all the time. So that's my life. That's where we're at. This has been your update on how sleepy we are in 2016.

#### Sydnee:

But I thought in, in light of the fact that Justin and I are very sleepy that we should do a sleep-related topic.

#### Justin:

Oh. Uh, cool. I'm not sure we've done all the sleep-related topics before.

## Sydnee:

No, I think...

#### Justin:

I think sleep is fascinating.

#### Sydnee:

I know you do. I know. Justin tried for a while... I think we may have even mentioned this on the... I think we talked about insomnia before, and that you did that, what is that sleep schedule called that, like, presidents did?

#### Justin:

Oh, polyphasic sleep.

#### Sydnee:

Yeah.

#### Justin:

Yeah, I tried that once. That did not go well.

He thought that we would just insert into our co-life, our couple life, 'cause it is, it is a life conjoined—

## Justin:

A shared life. Yeah.

#### Sydnee:

 $\ldots$  that we share. That he would just sleep every two hours or something or—

#### Justin:

Yeah, it's a weird schedule. It's like you, you. Uh, it's something like that. It's like every three hours, you sleep for 90 minutes or something like that and just keep the train rolling.

## Sydnee:

And that's just our life, is that he does that, and I sleep like, you know, a regular person. And we just live like that.

#### Justin:

I mean, like, it should be... It's worth noting, like, I did not do this for... I may have made it like half a day. Basically, I took a nap in the middle of the day, and that was my attempt at polyphasic sleep. So—

## Sydnee:

It was the same length of time that you managed to do the juice fast.

## Justin:

Yeah. I did the juice fast on-

## Sydnee:

That he started on trick or treat.

#### Justin:

Yeah. I made it... I basically just had some juice that day. [laughing] And then—

## Sydnee:

And then, and then ate trick or treat candy and that was it.

That was it. Uh-

## Sydnee:

Let's talk about narcolepsy.

## Justin:

Okay. Let's. I have a-

#### Sydnee:

Okay. Do you have anything to add? You sounded like you were gonna start us off.

#### Justin:

Well, let me kick it off. No, I have a—what I would describe as perhaps a layman's understanding of narcolepsy. I don't know if there's more to it, but—

#### Sydnee:

I think-

## Justin:

... from, from my limited layman's understanding of it, it is people who fall asleep, basically, when they're not trying to and at inopportune times.

#### Sydnee:

I think most people kind of get that perception of narcolepsy. And they s-I think you see images of that. I feel like I've seen that, that kind of trope before, like used for comedic effect in, in movies or television shows where someone has narcolepsy, and so the joke is that periodically they're just asleep. And so that's all that people know about it.

#### Justin:

Mm-hmm.

#### Sydnee:

It's actually a little more complicated than that. Um, and there are a lot of people who wanted us to talk about narcolepsy, so thank you to Ellie, and Erica, and Brett, and Jesselyn, and Sarah, and Allison, and Allie for recommending this topic. And I think there were probably many others on

Twitter and Facebook, 'cause it's not, it's not very common. I think it's actually considered kind of a rare disorder.

# Justin:

I know of-

# Sydnee:

It's like one in 2,000 people.

## Justin:

I don't think I've ever known anybody. You ever known anybody? You treat anybody that had it?

## Sydnee:

Uh, I personally know two people that do.

# Justin:

Really?

## Sydnee:

Yeah.

## Justin:

Wow.

# Sydnee:

And so, there you go.

## Justin:

Anybody I know?

## Sydnee:

I mean, no you don't.

## Justin:

No, okay.

## Sydnee:

But yeah, no, but I do and, uh, I have taken care of people with it. So I, I saw some numbers that were way more common than that. I don't know, maybe that is a point of dispute. It's still not completely understood, so you

find that, you know, like, people don't really know they have it because there can be different flavors, different variations.

# Justin:

Mm-hmm.

# Sydnee:

Um, so let's talk a little bit about what narcolepsy is before I kind of give you the history. So, first of all, the term narcolepsy comes from the Greek word narc or nárkē, narc.

# Justin:

Something like to, to sleep, sleepy something.

# Sydnee:

Well, close enough.

# Justin:

Dull, to numb.

# Sydnee:

Stupor, stupor, numbness.

# Justin:

I'm thinking of narcotics. That's where I'm going.

## Sydnee:

Yeah, same, same root word, you know-

# Justin:

Okay.

# Sydnee:

... narc. And then, um, lepsis which means, like, attack or seize.

## Justin:

Okay.

## Sydnee:

So-

## Justin:

So an attack of numbness or-

## Sydnee:

Stupor.

## Justin:

... stupor. Okay.

## Sydnee:

Yeah, or sleep attack is what-

#### Justin:

Sleep attack.

#### Sydnee:

... it was called at times. Throughout the literature, you'll see it reference that people had sleep attacks, and they're talking about narcolepsy.

## Justin:

Mm-hmm.

## Sydnee:

Uh, since the 1950s, we've really had a, a pretty good definition of what it is. Now, we're still trying to understand what causes it to this day, but as far as, like, how do you diagnose somebody with it? Uh, Yasin Daley at the Mayo Clinic defined what we consider the classic tetrad, the classic symptoms—

#### Justin:

Okay.

## Sydnee:

Uh, and those are excessive daytime sleepiness.

## Justin:

Okay.

## Sydnee:

So people with narcolepsy are gonna feel pretty tired most of the day-

## Justin:

Okay.

... untreated, especially. Uh, cataplexy.

#### Justin:

What's that?

#### Sydnee:

Cataplexy and, and what people think of as, like, sleep attacks, uh, get confused a lot. So, yes, people with narcolepsy are sleepy a lot, and so they may take, uh, frequent naps, and they may fall asleep very easily or very quickly during those naps, which I think is kind of what you see depicted on television.

#### Justin:

Mm-hmm.

#### Sydnee:

Like, the idea that somebody would just be sitting there and then have their head on their desk and passed out asleep. Um, but I think it often gets confused with cataplexy, which is when you basically just lose all muscle tone and drop to the floor. And it's usually in response to some sort of extreme emotion. Uh, it can be laughter. It could be stress, it could be excitement. It could be anything, and you just lose all muscle tone and hit the floor.

#### Justin:

Yikes.

#### Sydnee:

But that's not, but you're not asleep, so that's actually separate from the-

#### Justin:

Oh, so that sounds worse.

## Sydnee:

... the frequent-yes.

#### Justin:

Okay.

And not everyone with narcolepsy has cataplexy. Uh, you don't have to have all of these things to have narcolepsy, um, but these are kind of the most common things you'll see, and some people have all four. Uh, sleep paralysis is another common symptom which means, you're awake, but you can't move.

# Justin:

Okay.

# Sydnee:

And it's very scary. We'll talk a little bit more about that.

## Justin:

Is that different from cataplexy?

## Sydnee:

Yes, because cataplexy, is, you're awake during the day. You're walking around, talking, doing things, extreme emotion, bam, you're on the floor. Sleep paralysis is either while you're trying to fall asleep or while you're waking.

## Justin:

Okay. Got it.

# Sydnee:

Uh, and then there are also something that are very common. You can have these outside of narc— narcolepsy, but with narcolepsy are hypnagogic hallucinations, which just means when you're falling asleep.

## Justin:

Oh.

# Sydnee:

There are hypnagogic and hypnopompic hallucinations.

# Justin:

Okay.

## Sydnee:

And the hypnagogic ones are the ones when you, you're starting to drift off to sleep, and you can hear things or see things. They can be very upsetting and unsettling.

Weird.

## Sydnee:

Um, everybody can have those from time to time, but with narcolepsy, they're much more frequent.

## Justin:

Mm-hmm.

## Sydnee:

Many patients don't have all the symptoms. Only, only about a quarter, a fifth to a quarter have all of them.

## Justin:

Mm-hmm.

## Sydnee:

And then there's this proposed fifth symptom that you can see in a lot of patients with narcolepsy, which is ju— basically then their sleep at night is just disturbed. It's just a ve— they have very abnormal sleep patterns, if we were to watch their brain waves.

## Justin:

I wonder if it's... I wonder if it's like a causation of just getting sl— like, your circadian rhythms getting thrown off.

## Sydnee:

Well, that's part of it.

## Justin:

Not a causation but like a side effect, I guess.

## Sydnee:

I— in a— it is. It's one of those vicious cycles because of the disorganized sleep patterns throughout the day and then at night and, and but you, you see a lot of people who, you know, if we look at what we consider their sleep architecture, which is when we map your brain waves as you descend through the levels of sleep and then come back up to the more, you know, stages of wakefulness, um, a lot of people with narcolepsy, it does not go in

an orderly fashion, which is probably part of why they feel, they feel so tired too.

# Justin:

Mm-hmm.

# Sydnee:

But it all feeds into each other. Now, this may have been mentioned as far back as the early 1600s, when Thomas Willis wrote about certain patients that he saw. He was a physician, and he saw patients who had a sleepy disposition who suddenly fall fast asleep.

## Justin:

Mm-hmm.

# Sydnee:

Um, and that he was probably talking about, probably patients who had narcolepsy. Either that or Jughead, was who I thought of. [laughs]

# Justin:

Maybe he was talking about Jughead from Archie Comics.

## Sydnee:

Yeah. Maybe this was the earliest mention, history's earliest mention of Jughead.

# Justin:

That would be a very, very... 1600s, early 1600s would be a very, very early mention of Jughead. Jughead would need to be, like, a time lord or something as to a... Oh, no.

# Sydnee:

Jughead is a time lord.

# Justin:

I'm like your eyes just went wide as saucers.

# Sydnee:

The next doctor-

# Justin:

The next doctor is Jughead.

Oh, it's gotta be Jughead. Oh, that is a crossover. My nerd brain just exploded.

## Justin:

[laughs]

## Sydnee:

If I was the kind of person who had artistic talent or was, uh, apt to draw fan art—

## Justin:

Yeah, please send us your fan art. [laughs]

# Sydnee:

Please send me a picture of Jughead as the doctor, please.

# Justin:

And Tweet that to Sydnee McElroy, uh-

## Sydnee:

'Cause I can't draw.

## Justin:

Uh, so th— the, that wasn't Jughead.

## Sydnee:

Either way, Thomas Willis... No, it wasn't. Either way, he suggested caffeine.

## Justin:

But does that work? Does it help?

## Sydnee:

I mean, it'll keep you awake better.

#### Justin:

Yeah, I guess that's true.

## Sydnee:

Yeah. I mean, when we didn't have anything better, it wasn't, it wasn't a terrible idea. The first, better descriptions of narcolepsy we see in 1878 and

1888, by two German physicians, Westphal and Fischer, specifically, Westphal, who wrote a lot about this. And he noted that there were, um, these episodes of muscle weakness and that they could be triggered by strong emotions. This is where we get the cataplexy—

#### Justin:

Mm-hmm.

#### Sydnee:

... entering in. And he wrote a really thorough description of it, which was very helpful, you know, to try to understand what is this disorder. Um, but at the same time he, he linked it to a lot of the emerging psychoanalytic theories of that time period. He thought it was more of a something psychological, basically that was happening with these people, and specifically he had somebody out. Like, he, he, he mentions one patient who probably had narcolepsy, and then he talks about another patient, who probably didn't, but he links them together. And then blames it on excessive masturbation causing sleepiness.

## Justin:

Uh, I don't know. I mean-

## Sydnee:

That is not a cause of-

## Justin:

Okay, got it.

## Sydnee:

... narcolepsy. [laughs]

#### Justin:

I have a... I have a th— I have a theoretical question for you, and I don't wanna derail you—

#### Sydnee:

Uh-huh.

#### Justin:

 $\dots$  'cause, uh, we're running behind. But, you talked about the first doctor, d— uh, Thomas Willis, who described it as patients with a sleepy disposition who suddenly fell fast asleep. I think there's a, a very human impulse, and

we see it a lot in medicine, to, um, to, to talk about things in terms of nature back then, and then as we learn more to turn them into diagnoses. Do you, first off, is that right, that we, that we, that things tend to evolve from or they have a nature towards something, towards turning into a diagnosis? And is that... Do you think that's necessarily helpful for, for, for people to, to be able to di— "diagnose" themselves rather than think of themselves as having a, a nature or one way or the other?

## Sydnee:

I think it's a double-edged sword. I think that, I mean, when you're talking about historically, because that way, you're right, there, there are a lot of diseases, disorders that we would just think, like, well, that's how people are. That's just who they are. They're like that. And we blamed it on, they were too negative, or they were too anxious, or they worried too much or whatever. And, uh, that was because we didn't understand, uh, you know, anything about what was happening inside the body, certainly nothing on a molecular level, on a DNA level. Biochemistry eluded us. So, at that time I think it, you know, it was not helpful at all.

## Justin:

Mm-hmm.

# Sydnee:

Because it just made you say, "Well, your problem is that you gotta get your thinking straight or you've got to..." You know, it lead to things like, "You gotta go to church more," or something like, "And that'll fix your medical condition."

## Justin:

Yeah.

# Sydnee:

Um, I think it is important to remember now because I talked to people a lot about that. S— I would say a good example would be something like anxiety. There are people who have anxiety, and then there are people who, I— you know, we might say things like, "They're just a bit of a worrier." And they do, and they might be more prone to having, you know, anxiou— anxiety about isolated events than someone else, but it doesn't interfere with their daily life. It is just, kind of, just the person they are, but they still are happy, and it doesn't, you know, it doesn't interfere with anything.

# Justin:

Mm-hmm. Makes sense.

And I think that that's a big difference from someone who has anxiety and who needs treatment for that. So I talk to patients a lot about that, the difference between, "This is who you are," and then, "This is something that needs treated."

#### Justin:

Okay. I hate to derail you. You just finished talking about the guy who loves to masturbate all the time.

## Sydnee:

[laughs] So I, I wanna stop talking about him.

#### Justin:

Great.

## Sydnee:

Instead—

#### Justin:

Great. I mean, I'm sure he's a rich character with, uh, multiple layers, but...

## Sydnee:

I wanna to talk about, uh, our really, a lot of, uh, where the, the interest in narcolepsy and the research started was from 1888 or 1880, sorry, by Jean-Baptiste-Édouard Gélineau.

## Justin:

Okay.

## Sydnee:

Which is just a lovely name.

#### Justin:

Yeah, trips off the tongue.

## Sydnee:

He was a physician who studied a lot of different things but, um, one thing that he wrote a description of was narcolepsy. He observed this wine merchant that he was taking care of, who he wrote about how he was tired all day long, and he had up to 200 episodes a day of sleep attacks.

Okay.

## Sydnee:

Now, he was probably combining the sleeping and the cataplexy in this patient.

## Justin:

Okay.

## Sydnee:

He probably wasn't distinguishing in this, this description. Um, but, but one way or another, this guy 200 times a day was not being able to do his job.

## Justin:

Hachi machi.

## Sydnee:

He had previously been diagnosed with a, in the writing, he says he, you know, that we thought he had morbus sacer, which is the sacred disease, which was epilepsy.

## Justin:

Oh, all right.

## Sydnee:

'Cause we've talked about before, epilepsy, with it's, you know, kind of origins. And we talked about it biblically, and the idea that epilepsy comes from something divine or beyond us.

## Justin:

Mm-hmm.

## Sydnee:

Um, it was affecting his life so much, that he actually would keep his 13year-old son with him at all times at work to wake him up.

## Justin:

Oh, wow. So Take Your Son to Work Day every single day.

Every single day to keep dad awake.

#### Justin:

But he get to keep you awake, right?

#### Sydnee:

He did. It, it's interesting 'cause when you read this description of narcolepsy, he, he writes that the man, uh, claims that his infant son was conceived, and the way they, they say it is that it was during a moment that he was overtaken with the disease.

#### Justin:

[laughs] He's saying he was asleep—

## Sydnee:

So he was asleep is what he was saying.

#### Justin:

... asleep. I mean, he was asleep.

#### Sydnee:

That he actually co— that his, that his wife conceived a child while he asleep.

#### Justin:

Nice try. Nice try, fellow.

#### Sydnee:

Um— [laughs] Uh, you know, and that could have just been... It, it wouldn't be uncommon, especially with extreme emotions for him to have maybe post-coitally had a, had cataplexy that could have had happened.

## Justin:

Sure, yeah.

#### Sydnee:

Or he just fell asleep really quickly.

## Justin:

Or maybe he just fell aslee— You know, that happens to people, sometimes.

[laughs] Uh, no comment. He had... [laughs] He had many episodes of what was likely cataplexy, and those were well described. Like, he went through a lot of different situations that could do that. So playing cards and having a good hand, specifically.

#### Justin:

[laughs] The worst, the worst bluff possible. Like, the easiest tell you could possibly have.

## Sydnee:

[laughs] Like, they go to him. They're like, "Are you, are you in? Are you gonna fold? Are you gonna..." and he hits the floor, and you're like, "Well, I'm out."

#### Justin:

All right. Yeah. He, yeah, he, uh... I'm betting it's a...

#### Sydnee:

Uh, "Smiling at someone poorly dressed in the street."

#### Justin:

[laughs] We've all been there though. It's a nervous reaction. You don't wanna know what you really think. I get it.

#### Sydnee:

I like that. That's a reaction formation, and then cataplexy. So, uh, "Being surprised by a sudden danger." That makes sense. "Anticipating the pleasure of a good play in the theater."

#### Justin:

[laughs] Oh, man. I, I know that that puts me to sleep at plays a lot. And—

## Sydnee:

Can you imagine? If that, if that, if that is a trigger for cataplexy and narcolepsy is more common, there would just be, like, people laying on the sidewalk outside of Hamilton—

#### Justin:

Yeah.

... daily. [laughing] Uh, most notably, um, they describe in depth him looking at monkeys making faces in the zoo and having an event.

## Justin:

That's enough to put him to sleep?

# Sydnee:

Uh-huh. No, well, these are the cataplexy, extreme emotion, and he hits the ground.

# Justin:

Okay. Got it.

# Sydnee:

Um, he... Although-

# Justin:

And monkeys, by the way, if monkey see you do that, they will tear you apart. They will take that as a sign of weakness, and they'll jump out of the cage and, and tear your face right off.

## Sydnee:

So don't have cataplexy in front of a monkey.

# Justin:

Don't fall asleep in front of a monkey.

## Sydnee:

Um, he, he thought it was a neuroses of some sort. That was his... So this, again, is kind of with the, at this time period, like, this whole concept of the, the con— like, the subconsciousness and, and psychoanalysis comes soon after this, and so these things are being explored. He thought it was some sort of neurosis. Uh, he also hypothesized in several other patients, of, not the wine merchant, that it could have been the result of maybe too much sex—

# Justin:

Mm-hmm.

# Sydnee:

... using up all the oxygen that you need for certain parts of the brain that keep you awake. A lot of sex shaming here.

Yeah, it's weird.

## Sydnee:

Um, the treatments he used, the treatments that he would recommend for narcolepsy. Um, he would, he had already, by the way, made quite a name for himself, uh, treating epilepsy, this particular doctor, Gélineau, and he developed these Doctor Gélineau's tablets, which were just a combination of bromide and arsenic—

## Justin:

Ah, good.

# Sydnee:

... that were very popular [laughs] for the treatment of epilepsy.

#### Justin:

Sure.

#### Sydnee:

So he kind of took off of that, and arsenic was a treatment, strychnine, bromides, curare. There are a bunch of different things that he used, amyl nitrate, hydrotherapy, electricity. He would propose that you cauterized the nape of the neck. Um—

## Justin:

Any of those effective, actually?

## Sydnee:

None of them really worked.

## Justin:

Oh, no. Sure. Right.

## Sydnee:

So he, he eventually just kind of abandoned the effort.

## Justin:

Silly me. Silly me.

Uh, he basically said... Like, his last line on that was, "So, pretty much after nothing worked, the patient and I both agreed that we would go our separate ways," or something like, [laughing] "Well, it was fun while it lasted, but nobody is getting anywhere, so..."

#### Justin:

Uh, I wonder if he waited till he fell asleep to sneak out.

#### Sydnee:

It was really... [laughs] It was really, um, not until the early 1900s where we start seeing, like, caffeine is used still. We see ephedrine, like, is a stimulant that's used, and then finally in the 1950s where we see more stimulant medications like Ritalin, for instance, those kinds of medicines actually being used for, for, um, narcolepsy.

## Justin:

Ah. Are those effective?

#### Sydnee:

Uh, stimulants can be. They're not... This would not be, like, our best bet. There are... I'm going to tell you about... There's some other options, but yeah, I mean, they, they will keep you awake.

#### Justin:

No, okay. Great. Um, uh, I wanna hear, uh, uh, some of the others. What are we, we doing now?

## Sydnee:

Well, I'm gonna get to that, Justin. But first, why don't you follow me to the billing department?

## Justin:

Let's go.

[theme music plays]

#### Justin:

Um, is there anything, you know, you mentioned how I sort of had part of the picture, uh, uh, of narcolepsy. Eh, is there anything else that sort of factors into it?

Well, one thing that I wanted to feature a little bit more because it was one, it has been historically one of the most misunderstood parts of narcolepsy, and because, I mean, the idea of people being sleepy or, you know, uh, sleeping a lot, taking a lot of naps, even people passing out, is, is probably what they would have thought cataplexy was, just somebody passing out, is not a strange thing, and there are lots of different things it was confused with or, you know, that, people didn't necessarily have a lot of weird theories about that. But the sleep paralysis, that feature of narcolepsy has been, uh, turned into, I mean, kind of a folklore all its own.

#### Justin:

Mm.

# Sydnee:

So sleep paralysis can happen to people who don't have narcolepsy. Uh, you may have experienced it in your life. It is not, there... I don't wanna say it's common, but an isolated event of this once in your life, you may, you may have had one. I don't think I have.

# Justin:

Yeah, not to my knowledge.

## Sydnee:

Um—

## Justin:

I would probably remember that. I hope.

## Sydnee:

Yeah, I know you would. You know, it's, uh, let me say, I have definitely not. You would remember it, or at least, I would assume from the descriptions I've read. Um, but with narcolepsy, you might have it more, more often. And then, there are some people who don't have narcolepsy, who do have this commonly. So it's a parasomnia that, uh, that, which just means a disorder that happens around the time of sleep parasomnia—

## Justin:

Got it.

## Sydnee:

 $\ldots$  besides sleep. Um, but again, it's associated with narcolepsy. It is usually when you're falling asleep—

Mm.

# Sydnee:

... with narcolepsy, although it can happen when you're waking up too.

# Justin:

Okay.

# Sydnee:

And if you don't have narcolepsy, it could be either way. And what is basically happening is the REM cycles of sleep, which is when you dream, the rapid eye movement part of sleep, that's the part of sleep where you dream. Uh, that overlaps with waking. They're not supposed... Those are distinct times in sleep obviously, right?

# Justin:

Sure. Right.

# Sydnee:

One's not sleep-

# Justin:

REM is, like, right at the bottom of your, sort of, sleep wave.

## Sydnee:

Yeah, that's a very deep sleep. Um, REM sleep, it, during that sleep your body is actually, intentionally paralyzed. You know, it kinda turns off your motor centers, so to speak.

## Justin:

Okay.

## Sydnee:

Uh, reason being, this is a good thing. This is a fu— This is an important function. If it didn't, you may act out all your dreams.

# Justin:

That, that, I had never really thought about that, but that makes perfect sense.

So that's why if you ever get that feeling like you can't move, or talk, or whatever with a dream, that's in— that's intentional. Your body is doing that so that you're not wandering all over the place, hurting yourself while you sleep.

#### Justin:

Right. Okay.

#### Sydnee:

That's a whole other problem, if you don't have that, you might wander around, act out your dreams. That's, that's a problem too.

## Justin:

But a different disorder.

#### Sydnee:

Exactly. So the problem with sleep paralysis comes when you are trying to fall asleep, and the REM starts before you are actually asleep.

#### Justin:

Mm-hmm.

## Sydnee:

And this is a common thing with, with narcolepsy. Actually one of the ways, and I'll get into that, that we diagnose it is to see how long it takes from the moment you fall asleep to when you hit REM. It's supposed to take a while. People with narcolepsy, they are almost instantly in REM sleep.

#### Justin:

Does that workout sometimes? Like, sometimes I think that would be kind of nice. I have a hard time falling asleep.

#### Sydnee:

No. Overall, it doesn't. I mean, it, because they have all the symptoms. So overall, I mean, I know it sounds like a good thing, but overall it is, it, it, it's leading to more disorganized sleep.

#### Justin:

That makes sense.

Um, so either you enter REM before you're actually asleep, or you wake up and you're still in REM at the end of sleep. So these are the two times it can happen. Basically, you are awake, but you can't move.

#### Justin:

Ugh.

## Sydnee:

Now, you can imagine this is accompanied by fairly significant distress.

## Justin:

Sure, I can imagine.

#### Sydnee:

Yeah. That's not, that's not surprising. A lot of people with this will report a feeling that someone is in the room with them when it's happening, that there's an intruder there, and they can't do anything about it, some sort of alien presence, something scary, some non—specific threat. Um—

#### Justin:

You know, we give... A lot of times on this show, we give all time with people a lot of flak for like, "Why did you just assume it was angels or whatever?" But, like, on this one, I sort of wanna cut 'em some slack. That would probably be like pretty much the weirdest thing that had ever happened to you if you're in like... And, uh, uh, in the list of things that you could mistake for something otherworldly, "I got paralyzed and then there was a demon in the room," would be like pretty high on the list, I think.

## Sydnee:

Well, and that's, that's exactly what people thought that there was a demon in the room. That, that is a very common perception, and throughout, uh, history, and folklore, and legend, and, and kind of our common mythology, you see this across cultures. Now, one thing that I think is interesting to know, why, why do people have this sensation that somebody is in the room? This is probably related to kind of their survival mechanism.

## Justin:

Huh.

## Sydnee:

So in response to a threat, we have the fight or flight—

Right.

# Sydnee:

... you know, reaction, right?

# Justin:

Sure.

## Sydnee:

We know that if, if something threatens our safety or security, we get scared. We, our heart rate goes up. You know, we get sweaty. We, we get ready to run, or fight, or jump, or get out of there, right?

## Justin:

Okay.

# Sydnee:

Yeah, we know that response. Um, if you get some sort of stimulus that your body can't understand—

## Justin:

Mm-hmm.

# Sydnee:

... awake but can't move, usually I can move, but at this moment I'm awake, and I can't move. The, uh, basically, our body errs on the side of caution.

## Justin:

Assumes that... Okay.

## Sydnee:

We interpret that as a threat. We assume a threat. And so then we, we begin the feeling that there is a threat nearby. And then however you personify that is probably more related to your culture and your, you know—

## Justin:

Mm-hmm.

... you, what your personal beliefs are.

#### Justin:

Yeah.

## Sydnee:

... what you have watched on TV the night before or whatever.

## Justin:

[laughs]

#### Sydnee:

Um, so this was defined—

#### Justin:

That's why you shouldn't watch The Good Wife because then you'll imagine that The Good Wife is in the room with you, and she's trying to kill you.

#### Sydnee:

Is The Good Wife a scary movie or show?

#### Justin:

No, well no, but when you're paralyzed, and The Good Wife is lurking in the corner, like the girl from The Ring, then Good Wife gets scary real fast.

## Sydnee:

But she's a good wife, right?

#### Justin:

Yeah, yeah, when the lights are on, Sydnee. When the lights are off and you can't move then, you do not want The Good Wife in the room with you.

## Sydnee:

[laughs]

#### Justin:

Never watch The Good Wife, if you think you might have sleep paralysis the next night.

## Sydnee:

I didn't know The Good Wife was a horror program.

It's, it is when you can't move, Sydnee.

#### Sydnee:

So-

## Justin:

Most things are, like today's special.

#### Sydnee:

It w— [laughs]

#### Justin:

What if you, what if you imagine Jeff, that mannequin with the magic hat was in the room with you?

## Sydnee:

That was... Let's not get into that.

#### Justin:

I know.

## Sydnee:

Now that... Okay. Now, we're scared.

#### Justin:

Now, you're scared.

Sydnee:

Now, now it's scared.

#### Justin:

Now, I got in your head.

#### Sydnee:

Um, it was defined all the way back in 1755, uh, by Samuel Johnson, actually, in A Dictionary of the English language, where he groups in a description of sleep paralysis with nightmare. And you'll see that the word nightmare used, like, historically used to describe sleep paralysis, not just a bad dream—

Mm-hmm.

#### Sydnee:

... but used to describe sleep paralysis. It was long blamed on demonic possession, so either the reason this happened to you is because there was a demon inside you, or a very common myth is that there was a demon sitting on top of you.

## Justin:

Excellent, great.

#### Sydnee:

So you see this. There are a lot... If you Google this, sleep paralysis, or if you look for incubus or succubus, you'll find lots of imagery of a person asleep with a demon sitting on their chest. And it is because you get that feeling like, "I can't breathe. I can't move. I'm..." You know, you begin to feel like you're suffocating, and there's a scary thing in the room. There's something sitting on top of you. And, of course, when we talk about incubus and succubus, we're also adding to that, like, a possible sexual component.

## Justin:

Mm-hmm.

## Sydnee:

Because that's what... You know what an incubus is and a succubus? The, uh, incubus is male and succubus is female. They're demons who supposedly come and can take advantage of you at night.

## Justin:

Oh, got it. Okay.

## Sydnee:

Um, in Europe in the 1800s, it was very fashionable to blame food for this.

## Justin:

Uh.

## Sydnee:

That is where, I've always wondered about this, you know, in Dickens in A Christmas Carol, when Scrooge says—

Oh, the, uh, "...undigested bit of beef."

#### Sydnee:

Yes, that Marley, the ghost he has seen is, is a bit of beef, or a spot of gravy, or whatever he says he is. That is what he's referencing.

#### Justin:

Wow.

#### Sydnee:

That you might see ghosts, or see scary things, or demons, or whatever if you ate the wrong thing.

## Justin:

That makes a lot more sense.

#### Sydnee:

Yes. I had never understood that, but now I do. You were advised to avoid bad wine, fatty or greasy foods, get plenty of exercise. Uh, from this, throughout most cultures, you get the concept of the night hag. Uh, and the night hag is just the idea that there is this creature that might come, and sit on you [laughs]

#### Justin:

Ugh.

## Sydnee:

And suffocate you and prevent you from moving in the middle of the night. Um, and, uh, and I won't get into it. I mean, literally you can look. There, there's one in, in every country, in every history, in every different culture.

#### Justin:

Yeah.

#### Sydnee:

... throughout earth. They, they go by different names, but it's the same idea every time, and some of them are quite horrific. Um, people still recount, uh, people who have this will still, kind of, talk about, like, the feeling maybe they were abducted, or maybe they were aliens.

Mm.

# Sydnee:

So maybe some of those stories, maybe they're related to this.

# Justin:

Mm. Oh, yeah. That makes sense. You wake up. You can't move, and all of a sudden, if you're, especially if you're afraid of aliens already.

# Sydnee:

Exactly or an out-of-body experience or a near-death experience, some, so there's some theory like, "Well, maybe this was actually sleep paralysis." Um, there, there's a documentary about it called The Nightmare, that came out last year, that's all about this. Um, so—

# Justin:

It looks too spooky. We haven't work, worked up the nerve to watch it yet.

# Sydnee:

That's exactly right 'cause it looks very scary. Uh, now just to get back to narcolepsy in general so that you know kind of where we are, a lot of what we understand now about narcolepsy really comes from the discovery that this happens in dogs.

## Justin:

Mm. How weird.

## Sydnee:

So in the 1970s we did a lot of studies understanding, uh, narcolepsy in Labradors, Beagles and Dobermans.

## Justin:

Okay.

## Sydnee:

And that helped us a lot to understand human narcolepsy.

# Justin:

Sure.

Um, there's some thoughts that maybe there's an autoimmune role in some of it, that maybe it's an autoimmune disease—

# Justin:

Mm.

## Sydnee:

... um for, for especially people with cataplexy, but we're not completely certain. And a lot of it has to stem from that you don't have enough of something called hypocretin or orexins, which was just these things that are released in the brain from a certain part of the br— brain, and their job is to keep you awake.

# Justin:

Uh.

# Sydnee:

And if you don't have enough of those, you're not awake enough, so that's probably where it's coming from. We're beginning to understand that, and maybe someday we can come up with a really great drug that'll target exactly that—

## Justin:

Yeah.

# Sydnee:

... to keep people awake and to help treat narcolepsy.

## Justin:

I imagine there's not a huge market to get that drug developed though.

# Sydnee:

Well, it's, uh... Yeah. It's hard. When they're rare diseases, they're always harder to get enough research funding for that.

## Justin:

Sure.

Um, if you think you have it, they do a sleep study, and then they do a test, like I talked about, to see how fast... It's a sleep latency test to see how fast you get into that REM sleep, and that can diagnose it. Um, it's usually treated with things that will stimulate your cerebrum.

## Justin:

Mm.

#### Sydnee:

So stimulants that we talked about, there are things like-

## Justin:

Crank.

# Sydnee:

... Provigil.

## Justin:

Crank.

## Sydnee:

No, not crank. Nope. Nope, not crank. [laughs]

## Justin:

Crank is one.

## Sydnee:

And then, actually GHB.

## Justin:

Oh.

## Sydnee:

But unfortunately, we probably know as the date rape drug.

## Justin:

Yeah.

## Sydnee:

Uh, GHB is, actually does have a medical use for cataplexy.

## Justin:

Um, that, uh... that's wild. That's a lot. There's a lot deeper than I ever knew, Sydnee.

# Sydnee:

Yeah, there's a lot more to narcolepsy. It's very poorly understood, and we still needed... I mean, even on the medical end, we still need to do a lot of research to treat this better and to diagnose people better. 'Cause there are probably people who have narcolepsy who have not been, but the de—There's a huge delay in diagnosis.

#### Justin:

Mm.

# Sydnee:

A lot of people wait many years just thinking, "I don't know what's wrong with me, but I'm tired all the time," before they finally get diagnosed. So if you're having sleep problems, um, it may not be your baby. It's worth checking out.

# Justin:

Okay.

# Sydnee:

Going and seeing your doctor and seeing is, is there something else going on? You never know.

# Justin:

Thanks to maximumfun.org network for making us a part of their, uh, extended podcast family. And thank you to you for listening. Uh, we really appreciate you so much. Um, I don't think we recorded since we released this episode, so thanks to DC and New York for being so cool to us. We had a lot of fun. Yeah.

# Sydnee:

Yeah, the whole city is.

# Justin:

Yeah.

# Sydnee:

With the heat and all.

The whole... Yeah.

## Sydnee:

The whole city's there.

#### Justin:

They were lined up around several blocks to get into the shows.

#### Sydnee:

[laughs] Oh, thank you, all. That was a wonderful, wonderful experience.

#### Justin:

Uh, thanks to The Taxpayers for letting us use their song, Medicines, as the intro and outro of our program. Uh, that is going to do it for us for this week. Until next week, my name is Justin McElroy.

#### Sydnee:

I'm Sydnee McElroy.

#### Justin:

And as always, don't drill a hole in your head.

[theme music plays]

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