

Episode 03: Samantha only sleeps every 8 days

In this episode, we're talking with Samantha. And that's not her real name, by the way.

She has an interesting story, and it has to do with a medical condition that she's had since childhood.

Samantha has hyper insomnia. I'm sure you already know about insomnia. Maybe you actually experience it from time to time.

But what Samantha has is **HYPER** insomnia. That's more than just trouble sleeping sometimes. For her, it means that she typically goes about 8 days at a time without having any sleep. Can you imagine going more than a week with no sleep?

In this conversation, we talked about the medical aspect of it and what's actually going on. She also has some other medical issues that kind of complicate things. I also asked her the question she probably gets asked more than any other – what do you do with all that extra awake time? We talked about the advantages, and the disadvantages, of this particular condition. And I also asked her, "If there were a cure for this, would you accept it?"

There are some online resources available to learn more about hyper insomnia, and Samantha also has a blog where she talks about it in detail. I'll have those links in the show notes for this episode, which is at whatwasthatlike.com/03, since this is episode #3.

So thanks for listening, and I hope you enjoy my conversation with Samantha!

Scott

Samantha, thanks for coming on the show!

Samantha

Thank you for having me! I'm really interested to tell people about all of this because not many people have this.

Scott

Yes, it does sound like it's something that's interesting and unusual. What's the longest you've ever gone without having any sleep?

Samantha

I've gone 8 days without sleep.

Scott

8 straight days? It's hard for me to imagine that. You must have a hard time explaining that to people, right? How can you go all that time without sleeping?

Samantha

Most people that are close to me may have seen it. They've been around me my whole life. They've know that I don't really sleep even after sporting events or things like that. For people that haven't been around me and don't know me - once I explain about hyper insomnia - it's along chronic insomnia. Mine kind of roll one into the other because of unspecified test. Every time they've tested me for the sleep study, they found the same thing. But they also have seen a little bit different reactions to the medications that they've made me take as well.

Scott

Okay. So it's kind of an ongoing experiment, sort of.

Samantha

Yes, I've done my third sleep study. I've done one that was 2 nights long and both of the other ones have been a week long.

Scott

Is hyper insomnia an actual medical diagnosis? Or is there another name for it?

Samantha

They call it unspecified hyper insomnia.

Scott

Okay. What does that mean in layman's terms?

Samantha

In layman's terms, the easiest way to explain it is that my theta and delta waves run at the same time. The Theta is what tells the brain that it's awake, you're conscious, and you're doing things. Your delta is tells your brain to go to sleep and that's what helps you run through your sleep cycles. Mine don't stop - they run in unison at all times.

Scott

So, your waking and sleeping are...

Samantha

Yes, they do not shut off - they both run together. So, my brain literally thinks it's awake and asleep at the same time.

Scott

Wow. When did this first start?

Samantha

I don't really know. It's been as long as I can remember. I can remember it happened in my teenage years. I know when I was a kid, they did tell me that they had trouble putting me to sleep. So, I spent lots of hours reading because my mom didn't mind if we were up reading a book or if we were studying - as long as we were laying in bed and attempting to go to sleep.

Scott

How old are you now?

Samantha

I am 34 years old now.

Scott

Does anyone else in your family have this?

Samantha

No one else.

Scott

Have you ever met anyone else in the world that has it?

Samantha

I haven't yet. I'm hoping to. It'd be interesting to sit and talk with someone that goes through the same thing - that understands days becomes weeks, weeks become months.

Scott

Right, yeah. You guys would have a lot to talk about, I'm sure.

Samantha

I would hope so.

Scott

Do they give you medication to help with this? Or does it help at all?

Samantha

They give me Ambien, which works for anywhere between 4-7 days. But I don't want to take it every few days, or else it'll quit working.

Scott

Because you might develop a quick immunity toward it.

Samantha

Yes. They actually had to double the dosage twice. We figured that it would be best for me to just take it every few days instead of building a tolerance to it.

Scott

When you say that it works between 4-7 days, what does that mean?

Samantha

It'll help me fall asleep, but I will only be asleep for a couple of hours.

Scott

Alright, so you were first diagnosed with hyper-insomnia as a teenager. Was that when they actually decided what it was?

Samantha

No, I was first officially diagnosed 3 years ago. That's when we found out what was going on.

Scott

Ah, so it was that kind of a relief to know that the thing had a name, at least.

Samantha

At that point, no, because I have other medical conditions and we, kind of, attributed it to that. When we actually had gotten my pain and other issues under control, that's when we figured that we needed to look further into it. So, when I found out that it wasn't just the pain or anything else causing it, I was relieved to find out that there was something that was going on.

Scott

Did you have any other unusual health conditions?

Samantha

Not unusual. I just have a ton of other ones and nobody else in my family has any of them.

Scott

So what else has been going on that would add to your lack of being able to sleep?

Samantha

Here's the list. I have migraine, seizures, fibromyalgia, degenerative disc disease and, of course, hyper-insomnia. I know I'm forgetting something else but I don't remember what the other one was. I remember it at some point.

Scott

Well, that's quite a list.

Samantha

It's a lot to handle knowing that it's not just one thing - it's a group of things that we're trying to deal with all at one time.

Scott

And the medication for one might negate the medication for another or interact negatively, somehow - right?

Samantha

Actually, the doctors have been really amazing. They did the research on what medications I could use or not. It's not just what could actually work for me, but also what can react to others. So, we've done lots of research to find out things that will work for me - my doctors have worked with each other - which has been a really good thing for us.

Scott

Oh, that's great! Well, that's their job. Right?

Samantha

Well, when I was 7 years old, my doctors didn't want to communicate with others. They just want to deal with their one problem. So, I did take the time to find one that would be willing to look at my other records really well and actually make phone calls when we hit a stump on what to do next.

Scott

That's good! It's good that you found a good one. So what do you do with all of your time? I mean, you don't have to spend 8 hours a night sleeping. Well, how do you feel during all that time?

Samantha

This is a question I'm actually used to. I read a lot. I play video games. I have binge-watched all my favorite shows. There's really not much else. Right now, I'm picking up a new hobby. My

grandma was a tailor. She taught me how to sew when I was little. So, I'm picking that back up again after 15 years. It's frustrating but, at least, I have the time to work on things.

Scott

I guess. Yeah. Do you listen to podcasts at all?

Samantha

Actually, I don't. I've listened to one. I've got a friend that does them. Every time I sit down and start listening to one, I'm like, "Oh, I want to go read this but I haven't." I feel bad that I haven't sat down and listened to one of his podcasts so far.

Scott

Okay. Well, I'll tell you something. If you're not familiar with podcasts, now, you will be after being on one. There's a whole new world out there for you to explore and talk about any topic you can think of. There's probably a podcast on this subject - I wouldn't be surprised at all. So, maybe, it's something that you could look into.

Samantha

I think that is something I'll look into, definitely. Yeah.

Scott

I'd love to hear if you find anything. Do you ever lose track of time or what day it is?

Samantha

All the time. I will sit and think that it's Friday? No, it's Tuesday? I think it's Wednesday... And it's Thursday. But funnily enough, on Tuesday, I was texting my sister and telling her that I would be coming up on Wednesday or sooner. She goes, "It's Wednesday. Why aren't you here on Tuesday?" She looked and went... I said "It's Tuesday" and she went, "Oh, I thought it was Wednesday all day."

Scott

What can you do to make yourself sleepy?

Samantha

I've actually done a lot of yoga and meditation - that's kind of what I try to do to shut my brain down. Before I got injured with my back and neck, I used to work out a lot. I used to go to the gym. Every night, I took Zumba classes. I ran 4.5 miles a day, play soccer, or walk horses - because I used to show horses. I mostly work out just to wear my body down because if I didn't get it worn down enough, I could sleep a little - normally, it's just only a couple of hours. The worst thing now is I can't do those hard workouts. I can't go jog. I can't play soccer. So, I'm working on trying to find other things that will help me sleep now.

Scott

So, you can't do those other activities because of other health conditions?

Samantha

Yeah.

Scott

Right, okay. I wonder what else you can do, though. I mean, what else can you do? Obviously, it has to be something physically tiring.

Samantha

That's the thing. I've been trying to find out. I'm on a weight limit of 20 pounds, so I can't do the heavyweights, but we're trying to find something. I'm working on yoga right now, which is something that kind of helps a little bit. I can use it to, kind of, not think about anything else. I can just shut my brain down a little, so that helps a lot.

Scott

What about a treadmill? Would that be too high of an impact?

Samantha

I have a really bad knee. I already had meniscus surgery, so jogging is just not possible anymore.

Scott

Okay. What about just walking? I mean, of course, you gotta use your knee for that, too.

Samantha

I take my dog on a walk every morning. We do 2.5 miles a day, so that worries me a little bit. I get home when I am tired.

Scott

Good. Well, that's a good direction to head to in any way then. Are you able to have a job?

Samantha

No, because of the seizures.

Scott

Oh, yeah, of course.

Samantha

Yeah. That really messed me up with things. It's hard because I have to have someone else bring me to a doctor's appointment or anywhere I need to go to pick up medications.

Scott

Oh, yeah. Because with seizures, it would be dangerous to drive obviously.

Samantha

Yeah. Actually, before I was fully officially diagnosed, I got in a fender bender. Thankfully, nobody was hurt, but that was kind of a wake-up call that something was really wrong.

Scott

When I looked up the name 'hyper-insomnia' - just to do a little bit of research before a conversation - I found that there's a lot of information on hypersomnia which, of course, is excessive sleepiness. Actually, when I did the Google search, the first thing that Google search results say is, "Did you mean to search for hypersomnia?" For hyper-insomnia, there doesn't seem to be a whole lot of information available.

Samantha

No. It's one of the 14 types of insomnia - so, it lays underneath that. If you look at my medical records, they have hyper-insomnia, chronic insomnia, and two more types that go along with it. That's why they put me under 'unspecified' - because it's all layered together in me.

Scott

Okay. Now, I'm curious. What's the difference between hyper-insomnia and chronic insomnia?

Samantha

Chronic insomnia is where insomnia can last for months at a time - it's constant and never goes away. I wish I had written it down and had it in front of me. There are multiple times on my Reddit thread that I did I actually have a link to hyper-insomnia, but it goes into different types.

Scott

Okay. So, there's a bunch of different types of insomnia. We'll put those different types of insomnia in the show notes, in case people want to look at that.

Samantha

It's actually a website - sleepopolis.com - that goes into it and it defines all of them.

Scott

What was it called again?

Samantha

Sleepopolis - I might be pronouncing that wrong, but I have it on me and I can send it to you.

Scott

Okay, all right. I'll put all that in the show notes. So, how many people - as a percentage of the population - in the world have this? Do you have any ideas?

Samantha

Actually, I don't have an idea. I think if I had a little more breakdown of exactly what they would classify me as, it would be a little bit better than just being 'unspecified'. Otherwise, I don't have a clue of how many people would be under that category.

Scott

Okay. Yeah, because it's kind of broad. Let's go back just a little bit on our previous question - chronic insomnia sounds worse than hyper-insomnia.

Samantha

That's the part that makes me stay up for days - that's that section of it. Once I've been up and up and up, that's when all that sleepiness starts because I've been up for up to a week long. My body just gets so exhausted physically because when I don't sleep, I'd like to clean. I'm really OCD about things. I'll spend days - when I feel really good - to move around and do things. I'll clean baseboards, display cabinets - I would break them down clean. So, by the end of the day - after I've cleaned, I expected my brain to be tired and shut down, but no - my body's tired. So, I'll go lay down in bed all night and just get some rest for my body.

Scott

But your brain is still fully active?

Samantha

Yes.

Scott

Do you ever take sleeping pills?

Samantha

That's what the Ambien is for

Scott

Okay. So, when you do sleep, do you feel like it's a good quality sleep?

Samantha

Actually, I get tons of energy from my 20-minute nap. But when I do sleep - it's not that 8-hour sleep - I will go through the whole REM sleep. I have dreams. I have nightmares. I mean, when I shut down, it really gets kind of crazy. I'll have some of the most amusing dreams and get really fulfilled sleep.

Scott

How do you feel after you wake up from a long sleep? Is it just like other people or is there something different?

Samantha

I feel like the Energizer Bunny. I have tons of energy and feel like I could go all day long. I will start 20 projects and finish them on that same day. I'll start something and go, "Oh, I should do this. I'll start it in 10 minutes. Oh, I need to get this done! Oh, I need to do this!" By the end of the day, I have all these projects started. If nothing is finished, I have lots to keep me busy over the next few days.

Scott

Yeah. You got a lot to do over the next week, right? You must have quite a to-do list.

Samantha

Well, I'm one of those people who think if something needs to be done, just go do it. There's no reason to wait. There's no reason to say, "Oh, well, I can do it tomorrow." If you get it done now, you don't have to do it tomorrow. So, just get it out of the way!

Scott

On the other hand, if you save it for tomorrow, then you have something to do tomorrow.

Samantha

Right. That is true. But I can always find something to do. Right now, I'm playing Skyrim. I have a dozen different quests that I need to finish. So I'll take one day to do one and then go, "Okay, well, I'm gonna reorganize my closet." So I'll take the time to reorganize the closet and leave. Instead of playing all the way, I'll do half of it in the afternoon and the other half of it tomorrow. That way, I do have something to do.

Scott

Okay. Now, I know the gamers who are listening to this are gonna want me to ask, "What video games do you like?"

Samantha

As I just said, I love Skyrim. I've just started that. I'm thinking of restarting Tomb Raider - that was my first ever love. There's another one that I play a lot on multiple disks. Let's see. Those are my three big ones right now. I play a couple games on the PC. I just blanked out on their names because we're waiting for an update for one, so it's been about a year since we've played it. I can't believe I forgot it, but Diablo is another one that is one of my all time favorites that I've been playing, especially since they've added some new stuff. So, it's a little bit of everything.

Scott

What's the worst part of having this condition?

Samantha

Having too much time on my hand. As a normal people, you all get hours of sleep. So there's a big chunk of the day that you all don't do anything. To me, that big chunk of the day is actually time that needs to be filled with something and that's the hardest thing - just having too much free time can be a bad thing.

Scott

What's the best part of having all the time in the world to do anything?

Samantha

Most people who sleep for 8 hour or more don't have that extra time to do more things. But for me, I've got that time I can use to get stuff done.

Scott

Are you used to it now?

Samantha

I am. To me, it's everyday life. It's normal. It actually seems weird that people think so much.

Scott

Alright. If they came up with a magical cure for this, would you accept it?

Samantha

That's a 'yes' and 'no' question, actually. Yes, because I think it would be a good thing to get some sleep and not seem as tired all the time. When everybody's asleep, I'm not. Also, I like having all the extra time, especially when I find a really good book that I don't want to put down or I find a game or sport I'm really getting into. I don't have to look down and go, "Oh, no. It's 2.30AM! I've got to go to bed!" I got time - I can do this!

Scott

That's an interesting situation. Do you have any tips for people that have regular insomnia?

Samantha

Yoga and meditation - those are the two best things I have found to have some kind of peace running in my head.

Scott

Yoga and meditation? And what does meditation look like for you? Is that something you practice daily? Do you use guided meditation? How do you do that?

Samantha

No. I had a friend who was kind of big into it a while back. Her idea was just to sit in a chair, get comfortable, concentrate on breathing flow, and that's it. Just only think about the breathing until there's nothing else going on in your head. There are days that it doesn't do anything because I'm too worried about something or I'm too stressed or frustrated. On the days that I'm not, I can just really relax. I'll lay my head back comfortably and I'll have an hour or two just relaxing. There have been moments when it helps me to just fall asleep for like 20-30 minutes and I'll wake up a little refreshed after that - it's worth it!

Scott

If someone's listening to this, and they say, "Wow, I have 'unspecified' hyper-insomnia. We have that the same thing!" What would you tell them? What resources would you send them to, maybe, get some help?

Samantha

Find a sleep clinic. A lot of hospitals have them. Just go to your PCP and tell them, "I don't sleep. I'm going days or hours without sleep. Can you please find something for me? Can we get together with a sleep clinic and figure out what's going on?"

Scott

Okay. Do you think that, maybe, some sleep clinics have not even heard of what you have - because it's that rare?

Samantha

My clinic was actually, kind of, amused with me because when we did my second sleep study, it was for a week. On my second night out, I was laying there and trying to meditate. They wanted me to, at least, attempt to sleep. On the third night, they asked me, "This is something that was a little different that we noticed. We looked back and found it." So, I asked them what it was. They said that I laid down in the same position for hours and you didn't move. You laid there for three hours with not even one movement. When we asked you to switch positions, you did and the same thing would happen. They asked me how I did it, and I just told them, "I took breathing exercises. That's what I was using to attempt to sleep." They said that they actually never saw anybody who could do it without moving at all. So, that's the only part of it that was really different for them to see. In the sleep study, they should see enough odd cases like this to understand cases like mine - they would have seen a couple of different types of insomnia - so, that's where the unspecified came from, at least for me.. I don't know how the other doctor clinics would do it.

Scott

Right. Yeah, we should say here that neither you nor I are doctors. We're not offering any kind of medical advice - disclaimer here. If people want to contact you, I understand you have a blog?

Samantha

I do have a blog. It's called 'wingsforthewind'. I started a few years ago, so there's only a couple of posts there. Now, somebody actually asked me if I would do a daily one. So, I started that on Monday. I didn't do one last night because I didn't finish it - I got a little distracted - but I'm working on that right now. I do have it set up where you can ask me anything. You can comment on it now. If you have a specific question that you'd like for me to address, I will do that in my next blog after I see your comment.

Scott

Okay. What's the address for that?

Samantha

<https://wingsforthewind.wordpress.com/>

Scott

And I'll find that link and put that in the show notes as well. Well, Samantha, thanks very much. I appreciate you telling your story here today.

Samantha

Thank you for having me. It's nice to actually be able to get some of this out there. Hopefully, I can help somebody else with it.

Scott

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