Hadley

Vision Loss and Charles Bonnet Syndrome

Presented by Ricky Enger

**Ricky Enger:** Welcome to Hadley Presents. I'm your host, Ricky Enger, inviting you to sit back, relax, and enjoy a conversation with the experts. In this episode, Siobhan Midgley and Brittany Adams join us to discuss visual hallucinations with Charles Bonnet syndrome. Welcome to the show, both of you.

**Siobhan Midgley:** Thank you.

**Brittany Adams:** Thank you. Nice to speak with you.

**Ricky Enger:** Wonderful to have you both, and especially to talk about a topic that not a lot of people know about, and I think more people should. So I know this is going to be incredibly useful and informative for people. Again, thank you both so much for agreeing to join us. Before we get into talking about what Charles Bonnet is, why don't we just do a couple of quick intros. So, Siobhan, let's start with you. Tell us a bit about yourself and your background.

**Siobhan Midgley:** Sure. As you said, my name is Siobhan Midgley. I am based out of the Chicagoland area. I am a teacher for blind and visually impaired students as well as an orientation and mobility specialist. I also have worked as a certified vision rehab therapist. I currently own my own educational services company called Focus Forward Vision Services. I got interested in Charles Bonnet syndrome in my undergrad. My bachelor's degree is in neuroscience, and that was the first time I heard of Charles Bonnet in theory. But as I have begun working in the vision field, it is something that has come up over and over again, and I'm really happy that you guys invited Brittany and I to speak more on it.

**Ricky Enger:** Fantastic. Brittany, tell us a bit about you, your background, kind of who you are and as much as you're comfortable sharing with your vision loss journey as well.

**Brittany Adams:** Sure. My full title is Dr. Brittany Adams Yee. I am a fully licensed practicing clinical psychologist out of Illinois. My primary clinical interests surround children and adolescents, trauma, and health psychology. I live with cone-rod dystrophy as my primary source of vision loss as well as a secondary condition of narrow-angle glaucoma. My vision is a little interesting in the sense that I have no real usable vision in my right eye. I have a little bit of light perception, but that's pretty much it. And then in my left eye, I am legally blind, so I'm at 2200 visual acuity.

I've been losing vision since I was in elementary school but was not formally diagnosed with anything and had no idea I had a degenerative disease until my second year of college. I've been identifying as visually impaired and understanding that I have a disease for over a decade now. I'm here today, not necessarily as an expert, but because I have Charles Bonnet syndrome and I'm here to explain a little bit of my experience with it. Siobhan is the expert today.

**Ricky Enger:** Well, I think you're both experts in your own way because the lived experience is so very important. So we've thrown this term around a couple of times, and I kind of alluded to it in the intro about what Charles Bonnet might be, but for people who don't know what it is, Siobhan, why don't you give an explanation of what is Charles Bonnet. Why does it happen? How common is it? Just a bit of background on it.

**Siobhan Midgley:** Sure. So I guess it's good to start out with the name Charles Bonnet syndrome. Charles Bonnet was an 18th century Swiss naturalist and philosopher. He was the first to document in 1780, his grandfather's hallucinations. So these types of visual hallucinations have been probably happening since man was first made, right?

**Ricky Enger:** Yeah.

**Siobhan Midgley:** But Charles Bonnet happened to be the one to first document it in medical literature. His grandfather had cataracts and he was slowly losing his vision and he documented his grandfather seeing carriages and people, and eventually Charles Bonnet in his old age experienced visual hallucinations as he lost his vision. It was named after him in 1937. So Charles Bonnet syndrome, there's no pretty definition that is widely used among all doctors, and that is what can be difficult about this and getting a proper diagnosis because there is not a lot of research, although that is growing.

The elevator definition I give to clients is that as you are losing your vision, your brain is so used to that visual input, and it craves that visual input. So it's almost daydreaming where it's just going to make things up that contextually might make sense but is not necessarily reality.

For many people, it can be simple patterns, lights that kind of maybe look like fireworks. It can be floating across your vision. It can be stable. You are looking at it. There can be complex hallucinations where it's people, animals, bugs.

In the beginning when people don't necessarily know about Charles Bonnet or are a bit confused on what's going on, it might not be readily apparent that it is not real, that what you're seeing is not real. But eventually that should be the case where you can determine the difference between a visual hallucination and reality.

**Ricky Enger:** Yeah. That makes perfect sense. I think that because it's not so widely known about if this suddenly starts happening to you, you may not know what's going on. Brittany, can you speak to that? Can you talk about the first couple of times that you experienced visual hallucinations? What were you thinking was happening?

**Brittany Adams:** Yeah, sure. So the first times I started experiencing hallucinations was probably several months after I had been first diagnosed with cone-rod dystrophy. I think the very first thing I started losing was night vision and being able to see detail. But after I'd been diagnosed, I started losing more color vision and didn't know I was losing color vision at all. So what I noticed was happening is I was starting to project colors onto things that weren't the real color.

So for example, I was in film school at the time, and there was a classmate I worked with often who I thought had blonde hair and glasses. And there was a day when another student came into the classroom and was looking for this student and didn't know what he looked like. And I said, "So-and-so is over in the corner there and he's got blonde hair and glasses." And my other classmate is like, "Brittany, what are you talking about?" And I'm like, "What do you mean? He's got blonde hair and glasses."

"Brittany, he has red hair." And I'm like, "What are you talking about? He has blonde hair." And they're like, "No, Brittany, he has red hair. He has very obvious red hair." I'm like, "What?" And I look at my classmate and right in front of my eyes, his hair starts turning orange.

**Ricky Enger:** Wow.

**Brittany Adams:** Like right in front of my eyes. And then his hair is completely orange. And then from that day forward, every time I saw him, his hair looked orange. But I knew that even though his hair is actually orange, I wasn't seeing the actual orange hair. Clearly, my brain was making me think I was seeing orange hair.

And things progressed where things like shadows, moving dark stuff that I wasn't sure what I was seeing and things like that, they would start turning into other things. Early on, I oftentimes would see bugs that weren't there and not little cute bugs, cockroaches and centipedes and stuff. Yikes. Sometimes I would scream, I hate those bugs. And people would be like, "What is wrong with you? I got kind of embarrassed, so I would just stop."

I didn't lie about what was going on, but I would be very vague and say stuff like, "Oh, I didn't see that thing and I thought it was something else." But I wouldn't tell people. I thought I was seeing cockroaches and centipedes. Sometimes I thought I was seeing these deformed scary monsters and things like that. It would be mostly because I'm looking at something that's really there, but I couldn't make out or figure out what it was exactly.

Something I noticed myself, and experiences like hallucinations often take on an emotional property to them where they correlate to how you're feeling inside, and they can correlate to what's going on in the environment as well. I theorized in my head that my brain was projecting stuff out because I was losing my vision, and I didn't really talk to anyone about it.

I just assumed that’s what was happening and just rolled with it. But as I became more comfortable with and used to the fact that that was happening, the quality of the hallucinations I was having changed and they started becoming a lot more benign and sometimes even stuff that I like or found more interesting. So I stopped seeing bugs. I don't see bugs anymore.

**Ricky Enger:** Oh, good.

**Brittany Adams:** But I might see stuff like cats, like black cats or black birds and stuff like that that I like. If something is jumbled and I don't know what it is, I'm more likely to see something like a friendly fantasy type creature, a friendly giant or a nice-looking elf or fairy or something rather than a scary monster.

**Ricky Enger:** Wow. This is really fascinating to know that not only does it happen, but it has an emotional component to it. It means that it is possible to adjust and certainly when you know what's going on, it's easier to adjust. Now, I think Brittany, you are unique in that you have a clinical background, and you were able to figure out what was going on, maybe because of that background. For a lot of people, I imagine they might be like, "What is happening?"

We've mentioned people are not always so anxious to talk about, "Hey, you know what, I'm seeing bugs. There are things that I know are not there." Whether it's a mental health issue or a physical health issue, there's stigma around talking about things that are outside the norm. So I'm wondering, I guess for both of you, how do you come to talk about it? So, Siobhan, we'll start with you. How do you end up bringing this up with your clients? How can people talk to their doctor or their family and get over just that concern about, "I don't want people to think that I am experiencing something that I'm not, but still something is going on."

**Siobhan Midgley:** Yeah. I take my role as a vision rehab therapist very seriously in the aspect that I, as well as my other vision rehab therapists of the world, we are kind of the catch all. We see a lot of older adults and I am going to be the first point of contact for then saying, "Hey, let's try psychotherapy." So I am making sure that my other vision rehab therapists and myself understand first so that when we have new people come in, this is a part of your initial screening.

I will usually go through my own assessment of the needs of the client. And once I have built a solid rapport with that client, usually towards the end, I begin by asking very general questions, have you ever had any unusual visual experiences? And I just wait to see what they say. Doesn't necessarily mean that they're going to open up, but if they do, I then will start to probe a little bit more.

Have you ever seen objects or things in your vision you know aren't real? What are you seeing? How long have they been present? Is there any way you can bring them on or stop them? Very importantly, have you spoken with anybody about this and are they upsetting you? So that's just to probe what their emotions are behind it, whether the client has said, actually yes or no, I still will then go into what Charles Bonnet syndrome is, and let's just make sure it's on your radar regardless of whether you are having any of those symptoms or not.

**Ricky Enger:** Yeah, that makes sense. I'm wondering how commonly known it is. So if you were to visit your primary care physician or even your eye doctor, and Brittany, maybe you can speak to this, did you ultimately talk with medical professionals about what was going on? How informed were people about it? Or was this you figuring it out and telling them?

**Brittany Adams:** So I talked to two eye doctors and then I never talked to anybody about it again. It was more so me theorizing what was going on and talking to them about it. But I initially probed to see if they maybe knew what was going on first. The first eye doctor I talked with was in the context of them doing a color vision test and showing that I had significant color vision loss. And it felt like a confirmation of some of the thoughts I had because the first thing I was having hallucinations with was color.

I asked them if any of their patients ever had some of the experiences I had with the color changing and the hallucinations and stuff. And they just kind of looked at me and they're like, "No, I've never heard of that happening before. I have no idea what you're talking about, basically." And I was just like, "Okay, that's great." So I explained to them my theory of what was going on, and they were basically just kind of like, "Yeah, let's go with that. Let's go with that. That makes sense."

And then they never talked to me about it again, and I never talked to them about it again. I had one other eye doctor, I asked the similar thing, and this was later on when I was seeing more stuff and they had the same response where they're just like, "I've never heard of that before. I have no idea what you're talking about," type of thing. And so then I also explained to them my theory again, and then same thing, "Yeah, that makes sense. Let's go with that. That sounds about right." I think it was almost like a discomfort on their end too.

**Ricky Enger:** Yeah, it sounds like it. That's kind of disheartening too, right? Because what if you don't know, and you are expecting the medical professional to be the expert, and they're very much like, "Hmm, this is not my department. I don't know anything." Is that common from other clients that you've talked to as well, Siobhan? Is Brittany's experience the norm when it comes to this?

**Siobhan Midgley:** Unfortunately, yes. One thing that I've noticed with the research articles that I've combed through, specifically in the US, there is not much research being done. Most of these articles are coming from the UK, Australia, Canada, but there is a sore lack of resources and understanding in the states. That's slowly changing. I can't put it all out there yet, but we're slowly trying to build more resources here. Not only people with CBS themselves, but like I was saying, the professionals, the optometrists, the ophthalmologists, the vision rehab therapists, the teachers of the visually impaired, all of these people that see these people having the understanding and not being caught off guard when somebody comes to them with this.

But I do recommend the American Society of Retinal Specialists, they have a one-page overview sheet that is a quick rundown, and when I'm speaking with a client that wants to go to their doctor, I will print it out and say, "Bring this with, talk about what you're thinking this may be." You can be informed going into it and feel more empowered to explain what's going on and maybe hopefully be taken seriously.

**Ricky Enger:** Wow. We will have a link to that sheet in our show notes so that you'll be able to print that out and take it into your doctor. And it sounds like it is incumbent on you as the person experiencing it to learn as much about this as you can because you may be the one informing other people as opposed to the other way around. That's what makes podcasts like this so useful because if you're experiencing this and you didn't really have a name or a reason for it before, now you have something that you can take to your own medical professionals.

So as we're wrapping up, I feel like sometimes just knowing what to expect with any sort of diagnosis or anything that's happening sometimes just knowing what that is and what to expect, it's no longer the unknown, it alleviates some of that anxiety. I'm wondering if each of you can give some tips whether it is practical or emotional or a bit of both for how to best manage Charles Bonnet.

And again, whether it's emotional, social, practical, anything you got that you just want to say to someone listening who may be experiencing this? Brittany let's start with you.

**Brittany Adams:** Yeah. I experienced it as something that got better because it became something that was just so integral in how saw things out in the world. I started using it and forming a relationship with it, and it helped me understand my mind better. So it's more than just a visual experience. It helped me understand how I'm feeling better. I used it as a source of checking in with myself and checking in with what's going on around me, which I look at it as a wonderful resource in a way that other people don't really get access to.

I sometimes learn things about how I'm feeling that I didn't know was there because I'm seeing something and then thinking more about it. But the other thing I'd say is you don't have to take it so seriously either. I definitely have had many experiences with CBS that have been hilarious, really fun, beautiful, existential. Just allow yourself to take in what's going on.

**Ricky Enger:** I love that. That is such a wonderful perspective. I love it. Siobhan, anything that you would add to that or anything that you want to leave listeners to think about if they're experiencing it now or maybe will at some point. Anything that people really should know or take to heart?

**Siobhan Midgley:** In the same vein as what Brittany says, I always tell my clients, get to know them. Get to know your hallucinations whether that means from an emotional standpoint or from an environmental standpoint, what brings them on. Oftentimes lighting can affect them. It's not everybody's goal to get rid of them, and it can be. And if it is affecting your life in a negative way, there are some practical things.

Now, I consider these the tools in the toolbox. It will just give you some ways and maybe it will work, maybe it won't. Maybe it will sometimes. But try changing the lighting, whether it's from dark to light or light to dark. I have clients who will reach out to touch the object and that gets them to go away, moving around or completing a task, giving your brain something to think about, maybe something you enjoy doing. Give it some of that stimulation that it wants.

Also, I always recommend to my clients, while I've said that we don't have a lot of resources here in the states, we do have a Dr. Gary Cusick. That's C-U-S-I-C-K and he has a Zoom support group for people with CBS as well as for their caretakers. He has given people a space to talk about what's going on, to share their experiences, to hear other people's experiences, and also a space for caretakers and those people that it may be difficult, especially when you are not only taking care of someone with CBS, but maybe an older family member, giving them space to talk about the triumphs and the difficulties. He has a great resource. Him as well as myself, I am available to be reached out to in case people would like more information.

**Ricky Enger:** Fantastic. We'll have all of that stuff in the show notes as well. I'm just delighted at the fact that both of you could come and share, and I guess put a face on this, something that initially seems like it could be a little scary. It's not commonly known about, and instead we've taken it from that to something that honestly, you can have fun with if you want to, or it's a chance to get to know yourself and your mind, and there are resources for talking about it in a practical way too. So this has been incredibly useful. I'd like to thank you both so much for taking the time, stopping by and sharing your experiences. Thank you.

**Brittany Adams:** Thanks, Ricky.

**Siobhan Midgley:** Yeah, thank you for having us.

**Ricky Enger:** Got something to say? Share your thoughts about this episode of Hadley Presents or make suggestions for future episodes. We'd love to hear from you. Send us an email at podcast@hadleyhelps.org. That's podcast@hadleyhelps.org or leave us a message at 847-784-2870. Thanks for listening.