Hadley

Visual Hallucinations with Vision Loss: What You Should Know About Charles Bonnet Syndrome

Presented by Ricky Enger

**Ricky Enger:** Charles Bonnet syndrome is a condition you should know about as it can affect people regardless of the cause of vision loss. In this episode, Eva Potts, co-founder of Mary Carmel's Light, joins us to discuss Charles Bonnet syndrome and support for those who have it. I'm Ricky Enger, and this is Hadley Presents. Welcome to the show, Eva. How are you?

**Eva Potts:** Thank you, Ricky. Happy to be here.

**Ricky Enger:** It is wonderful to have you, and especially it's wonderful to be shedding some light, if you will, on Charles Bonnet syndrome, which a lot of people actually don't know much about. We did have a previous episode on this topic, and we were amazed to discover how many people said, "Wow, I didn't know about this, I didn't know what this was, and this was really helpful." But turns out that not everyone has listened to that episode just yet, so why don't we just start from there. Give us an intro, tell us a bit about who you are and a bit about what Charles Bonnet syndrome is for people who don't know, never heard of it before.

**Eva Potts:** So I'm Eva Potts, and I am the co-founder and president of Mary Carmel's Light. Charles Bonnet syndrome is a physiological condition that affects anyone with low vision. It can be low vision brought on by natural causes, accident, injury, disease. Any reason that you can lose your vision, CBS can suddenly impact your life.

What begins to happen is people have these silent visual hallucinations, and they're immediate. There's no warning, there are no symptoms that would occur before other than vision loss. These silent visual hallucinations can either be very simple, like geometric patterns, or they can become very nightmarish, almost like seeing a horror story or people invading your home. The difference between this and other types of diagnosis that would include hallucinations as one of the symptoms is that they're not tactile or auditory. So they're silent, but they're disturbing.

If you can imagine for a moment, when you don't have vision, your brain is starving for visual input. And since your eyes are not feeding your brain that visual input, it's going to search for it. And unfortunately, it does so in a way that causes some people to have these hallucinations. They're clear as a bell in front of them, which is very disturbing because they've had a loss of vision. How in the world can I be seeing this so clearly and have this loss of vision?

The problem with Charles Bonnet syndrome right now, well one of the problems, is that people are being misdiagnosed. Because Charles Bonnet syndrome has not been given a proper designated billing code for diagnosing, because with the proper billing code, there's reimbursement for doctors, and since we don't have a proper billing code, it gets misdiagnosed very quickly, very easily. People are not thinking through the consequences of these misdiagnoses, and I know this from a personal standpoint. So the misdiagnosis for Charles Bonnet syndrome in older people are dementia, schizophrenia, severe bipolar disorder, Lewy body dementia. Sometimes it can move over into the realm of just being considered psychotic.

**Ricky Enger:** And so think about that, you're a person with vision loss and you know that something is happening because you're seeing these things and they aren't real. And you go to the doctor, and they give a diagnosis that is sometimes, "We don't have any treatment for that, but what you have is dementia." I can imagine that it impacts people in a really negative way. In fact, this happened to your mom. Can you share that story of how that came about? And thankfully, your mom eventually got the correct diagnosis, but it didn't happen immediately, right?

**Eva Potts:** It did not. Unfortunately, there was a lot of confusion for her. Our mother lost her vision to glaucoma and went through a process of angular closure, which is very painful. It's a very painful way to lose your vision. Any pinpoint of light that comes through is extremely painful, the headaches, the eye aches, even getting her to a doctor’s appointment was absolutely painful for her. Mom didn't tell us for a while what she was going through because she didn't understand it. And as her vision declined, it intensified for her to where she couldn't help but tell us, because she was seeing things that were terrifying for her.

When she finally started to share her experience with us, some of the people in our family were very convinced that mom was either losing her mind or she had dementia, and we needed to fix that. Well, we went to doctors, and her primary care physician at the time felt she was fine. They didn't know what was wrong with her. However, her optometrist knew about Charles Bonnet syndrome, but there was nothing they could do about it. He had heard of it, didn't have any information, and wasn’t very clear on how to help her with anything. And so it got worse because we didn't know what to do.

The reason we found the diagnosis was our Aunt Rosemary was sitting in her room constantly Googling my mom's symptoms. There were no signs of dementia, no signs of the hallucinations being tactile or auditory, what could this be? And she finally came across Charles Bonnet syndrome. She shared that with my brother and I, who were our mother's primary caregivers, and so we started finding out as much as we could, which as you have already mentioned, was basically zilch. There's not a lot of information out there.

**Ricky Enger:** Yeah, very little.

**Eva Potts:** How do you help somebody who's going through this? What are the steps that you take to reassure them that they're not in danger, that this is something that they're seeing, but it's not actual? It's real to them, but it's not actual. Back then, we didn't know any of this, so we really didn't know how to help her other than to constantly reassure her that if we saw something like she was seeing we would be proactive, we would be taking care of it, we would stand in front of it for her, we wouldn't let anything hurt her.

Sometimes they were very pleasant hallucinations such as writing on the wall. They would just take so many different forms for her. And so we were never quite sure what mom was experiencing. All we knew was what we were experiencing. Time went on and things did not improve with mom because we didn't know how to help her. We were keeping her as comfortable as we knew how, making sure that she was well-cared for, her medications were being given to her. She was in her home, and we were just 24/7 had somebody with her. One day she was taken to a doctor and unfortunately, she was in the middle of a hallucination, and without any proper assessment, this doctor shamefully gave her a dementia diagnosis. Had her caregiver not been with her, we would've never known what had happened. And so when we found out, we were mortified for her because this was the beginning of a road, we didn't want mom to go down.

**Ricky Enger:** Sure. It was not true. So there's a lot that happens if you're diagnosed with something that isn't what you have, then naturally treatments for that thing are not going to help you, right?

**Eva Potts:** Correct. Having worked with people in the past with dementia, I knew my mom didn't have it. I just knew she didn't. But I'm not a doctor and I'm not a medical professional, so I would say, "I think mom needs an assessment." Mom finally came to live with my husband and me. She was okay with it, there were just some necessary steps we had to take, and I got her to a neurologist. The first time she went, she was hallucinating, and the words were given to her to memorize, and she got them jumbled up and she didn't pass the first time. The doctor said, "Mary, don't worry. I don't diagnose somebody with dementia until I've visited with them three times," which I think is brilliant.

**Ricky Enger:** Absolutely.

**Eva Potts:** He said, "Because there's always anxiety involved. You have to give that person space." He said, "You're going to have two more visits and we're going to do some tests. I don't want you to worry. You did pretty well the first time, not great, but you did okay." So we were going to go back in two weeks. During that two-week period, mom was so quiet, and I couldn't figure out what was going on with her. She said, "I'm good. I'm good." The hallucinations had really lessened a lot. So we're going to go to coping mechanisms and I'm going to explain how that really probably helped. I could tell she was concentrating.

When we went to the doctor, to the neurologist the second time, she was really hyped up to do it. She was never really hyped up to go anywhere. She was up, ready to go, wanting to get dressed, wanting to get in the bathroom. Mom was 86 when this was going on. So we got her there. She gets in the door and she said, "I've got to see him. I've got to see him right now." And then, "Ma'am, we have to wait." She goes, "Oh, I've got to see him now." And he heard her, so he came out and said, "Mary, calm down. What's wrong?" She busted out those seven words from the two weeks prior in order, in order-

**Ricky Enger:** Oh my goodness.

**Eva Potts:** ... in the order that they were given to her. He got her file, he looked at me, he goes, "Well, she doesn't have dementia." But I said to him, I said, "What do you think about Charles Bonnet?" and he said, "It's definitely a possibility." He said, "But I don't diagnose that." So he couldn't properly give her a diagnosis.

And it's a very important component of this, I can tell you from everybody I've talked to in our support groups, which we'll also address in a moment. There are so many people in our support group. One that I can never forget said, “That's just Antoinette. I'm okay with losing my vision, but I'm not okay with losing my mind." That is something that I think everyone with Charles Bonnet first thought is, "Wow, I am not okay. Something's wrong. People are going to think I'm mentally ill." And that's why people isolate. We also had another support group member who lived five years without telling her husband that she was hallucinating. And herein lies the conundrum. So in the words of Judith Potts, two things can be true at once. Just because you have Charles Bonnet doesn't mean that you can't get dementia.

**Ricky Enger:** Absolutely.

**Eva Potts:** Right. That if you're a younger adult that you can't have schizophrenia or have a psychosis diagnosis. The thing is, we have to make sure that we're treating the right symptoms. And if it's just Charles Bonnet and we're giving people medications for things that don't treat it... nothing treats it. We don't have a cure for it. We don't know of any pill that works for it right now because there's no research behind it, because it's not being recognized. So here we go, it's all cyclical, right? It's like this roller coaster you can't get off of because you're going round. We need a billing code, we need research.

**Ricky Enger:** Right. Right.

**Eva Potts:** We need doctors behind us. I think the one thing that sticks in my head, Ricky, more than anything, is as a doctor, that Hippocratic Oath, "First do no harm." If you know that this is what somebody's dealing with and you know this could be the diagnosis, just because you're not going to get reimbursed for the visit and you lay another diagnosis on somebody, kind of shameful, isn't it?

**Ricky Enger:** Absolutely.

**Eva Potts:** I mean, talk about integrity. I'm not saying all doctors do that. We have a lot of people in our support group whose doctors do say, "We truly believe you have Charles Bonnet syndrome. Unfortunately," and I love this response from them, "unfortunately, we don't have any answers for you. Here are some resources that you might be able to find on the internet." They don't leave them hanging. They just say, "I can't help you with this. I don't know how to help you." But at least they give them-

**Ricky Enger:** A place to go, somewhere to turn.

**Eva Potts:** They validate them.

**Ricky Enger:** I think that that's really important because it's one thing to say, "I don't know the answer. I can't help you. I hope someone else can." They're still left back at square one. If doctors do have some resources that they can point people to, that at least gives them a next step on their journey. That actually is a nice way to segue into my next question, really, which is I'm hoping you can talk about Mary Carmel's Light, which you founded in honor of your mom once she passed.

So after having seen all of the damage that a misdiagnosis can do, after having seen just how little information was available and knowing that there were other people who could potentially be suffering the same fate as your mom, you and your brother decided to do something about that. So can you talk about what your organization does? It is a nonprofit, and you've alluded to support groups, and we'll certainly get into that. But yeah, what can people expect to find if they visit your website or contact you?

**Eva Potts:** So Mary Carmel's Light began in 2021. Mom passed in 2020, and I stayed in touch with Dr. Gary Cusick and Judith Potts. They were very supportive of my grief journey. Dr. Gary Cusick said to me one day, "I feel like your journey with this isn't over." But we started talking about it and talking about it. One day I woke up, my husband was sitting out on the deck, and I said, "Honey, I think I need to do something about Charles Bonnet syndrome." He goes, "Well, what are you going to do?" I said, "I think I need to start a nonprofit." And he goes, "Oh, are you sure?" And I said, "Yes, but I have no idea what I'm doing." Which is true. I had worked for nonprofits in the past, Easterseals UCP probably being the largest one, and I always had a passion for helping people. I worked as a social worker for close to 20 years on some level, so I have a lot of empathy for people who are in need. I contacted my brothers, and I said, "Would you like to do this with me?"

And so we came up with the name. We had just decided that although Mom's journey with Charles Bonnet had ended, ours hadn't. It was the visceral feeling of knowing that there were still people out there left with no resources when their loved one is diagnosed with this, that feeling of being abandoned by the medical community, being abandoned by the ophthalmology community, just nobody's listening, nobody's paying attention. We weren't sure how we were going to start this or where it was going to roll to, but we put together as many people as we could that had a lot of the same beliefs or had experience with it. I have to say, we worked really hard to put our board together, and everyone on our board, Charles Bonnet syndrome, has either touched their life in some form or fashion or they've worked with the visually impaired and it's touched their lives. And great news, we just brought on a medical director.

**Ricky Enger:** Awesome.

**Eva Potts:** He is just now retired from the Mayo Clinic, Dr. Leo Skorin. We see great things coming as we revamp our 501c hopefully to include research. Not doing the research ourselves but connecting ourselves to research and searching out those projects that might help us.

Mary Camel's Light is a resource for not only people living with Charles Bonnet syndrome, but also for caregivers. We offer a helpline that operates 24/7, and if you don't get somebody, we do call you back. We offer support groups once a week, every Saturday from 12:00 to 2:00. The first hour is spent talking about Charles Bonnet syndrome and letting those people who live with it share their experiences, hopefully glean some knowledge from others about how to use coping mechanisms to live with their Charles Bonnet syndrome.

And then the second hour is dedicated to the caregivers, trying to help each other understand how to cope with Charles Bonnet and how to help the people that they love, because there is a strong sense of helplessness with caregiving when it comes to Charles Bonnet syndrome. It's not the fault of the person living with Charles Bonnet by any stretch of the imagination, but the syndrome itself can present itself on so many different levels. It's like a box of chocolates, and I'm going to steal that from Forrest Gump, you never know what you're going to get. Every day is different when you are caring for somebody with Charles Bonnet syndrome.

We're finding that the way somebody copes with Charles Bonnet syndrome has a lot to do with personality type. So if you're a really positive person and you're one of those cheerleader people and you have this positive outlook, we have learned that these people seem to be not as engaged with their... They don't like the word hallucination, but I'm going to use it because it's the correct medical term for these purposes.

**Ricky Enger:** Sure, yeah.

**Eva Potts:** But they like to call them visions or episodes. They don't engage with them as often, and they seem to have more of the capacity to go, "Okay, I know this isn't real. I've got to put this somewhere." Then if you have somebody who's middle of the road, sometimes it's intense, sometimes it isn't. They know that it's real to them, but it's not actual. But sometimes it's still very disturbing. And then if you have a personality type of somebody who's fear-based, we find that those are the individuals that if they're very anxious, if they've had some trauma in their life, if they haven't worked things out in their lives, the CBS tends to prey upon those fear-based anxieties.

And so we're learning a lot just listening to people in the support group and gleaning what we can. It helps us on phone calls. It helps us to ask certain questions when people are experiencing Charles Bonnet, wanting to come onto the support group. And the reason we have to talk to people is we have to also be sure that that's exactly what we're dealing with, because sometimes there could be other things going on with somebody. When you bring them into a support group, you don't want to rock the boat in the other direction for either person, because support means you meet somebody where they are. You expect anything from them, and you shouldn't put any boundaries on them to talk about what they need to voice and what they need to get out.

**Ricky Enger:** So you're mentioning having these discussions with people who call and people who want to get involved. That seems to indicate that this is open to more than people who are just local, are you having these on Zoom? Or if someone is listening and either they're experiencing this or maybe their spouse is looking for answers as well and they want to be involved in this, what is that process like and how do those support groups meet?

**Eva Potts:** That is a very good question. So yes, we take phone calls from all over the US and Canada. There's a helpline, which is (704) 389-0160. That's where you call for information on how to join the support group or if you have questions about Charles Bonnet syndrome. If you're not sure that's what's going on, we're not doctors or medical professionals, so we don't offer medical advice or say, "This is what you need to do next." We try to guide you from the experience that we've had. I normally put everyone in touch with Dr. Gary Cusick, and from there, if somebody wants to come to the support group, it's a virtual support group on Saturdays, and you receive a Zoom link and you just join. It's Eastern Standard Time, so that 12 o'clock on Saturdays, Eastern Standard Time, and it goes until 2:00. We often run over quite a bit.

**Ricky Enger:** There's a lot to talk about.

**Eva Potts:** There is, and we're growing. Ricky, at the end of the day, what needs to happen with Charles Bonnet is it needs to be normalized. If you go to a doctor and you're having trouble with your vision and it begins to decline, for any reason, your doctor should be able to say to you, "Hey, you might experience Charles Bonnet syndrome because it happens sometimes when your vision starts to decline. If you're injured or you're in an accident and you're in the ER and your vision's been affected because of accident or injury or you get sick, all of the people, for any reason that they're seeing a doctor and their visual acuity is dropping, that doctor should say to them, "This is something that might happen to you. Don't be afraid. It can't hurt you. It's disturbing for some people. Here are some resources," or "You might want to Google some resources." But at least give them a name of something that matters, right? So give them hope.

Research is showing over in the UK, and we haven't gotten our own research done here in the US because we don't have the money yet for the research, we're going to get there, but in the UK what they have discovered is approximately one in every three people, one in every three people with low vision or who have gone blind after being sighted get Charles Bonnet syndrome or experience Charles Bonnet syndrome.

**Ricky Enger:** And that's an incredible statistic for something that not even one in three doctors probably know about Charles Bonnet. And as you said, this should be normalized. I know that on your site you have a link to a letter for doctors. I believe that was written by Dr. Gary Cusick, maybe.

**Eva Potts:** Yes.

**Ricky Enger:** You can print that letter and take it to your doctor. It may be you educating your doctor, "Could this be it? Can you look into it?" That helps if you're experiencing as well as anyone who comes after you. And so I think it is essential that the word get out there that this exists and that people can be given some resources to help cope with it. And that's what Mary Carmel's Light is doing.

**Eva Potts:** When someone contacts me, I get their email address, and I send the letter in. There's also an information packet that I send to them that is just full of information. I truly believe that the packet and the letter should go out to everybody. Anybody that wants to send me their email address, I will send this to you because it's getting the word out too. It's educating the public.

**Ricky Enger:** Absolutely. Thank you so much. It's been really, really informative just to learn about what Charles Bonnet syndrome is, and I think more importantly, learn about what support there is for it. There are ways that you can manage what you're going through. There are ways that you can get support either as a caregiver or as someone with this syndrome and mindfulness techniques and all kinds of things.

Certainly at Hadley we know the importance of talking with people who are going through what you are going through so it doesn't feel like you are the only person. You're not alone. Eva, I want to thank you so much for stopping by, sharing your mom's story and sharing about the organization that you founded. We will have the information for getting in contact with Eva and Mary Carmel's Light in our show notes. Again, thank you for stopping by, and thank you all so much for listening.

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 P-O-D-C-A-S-T@hadleyhelps.O-R-G. Or leave us a message at (847) 784-2870. Thanks for listening.