

## Audio file

[LBS2E8- Charles Bonnet Syndrome 101 With Dr. Keith Gordon.mp3](#)

## Transcript

Jeff: Hello everyone! This is Jeffrey Rainey, producer of the Living Blind podcast. On behalf of the entire team here at BALANCE, I would like to personally

thank each and every one of you for listening to our show.

Whether you've been listening for a long time or just tuning in for the first time, welcome. And that's why we want to hear from you. Do you have lived experience with blindness or partial sight? Do you have an interesting personal or professional story to tell? Do you want to share your experiences with a worldwide listening audience of people with vision loss? Do you participate in work, leisure, sports, volunteer or everyday living activities using adaptations that would be helpful for others to know about? We are currently seeking guests for season three of Living Blind. If you are interested in being interviewed, have a topic you would like us to cover, or a person you would like us to interview, please send your ideas and expressions of interest to living blind podcast at [balancefba.org](http://balancefba.org). We'll be on with the show in just a moment, after this message.

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Naomi: Welcome to living blind. I'm your host, Naomi Hazlett, and this podcast is brought to you by BALANCE for Blind Adults, located in Toronto Canada. This season of living Blind is sponsored by AMI. Here at Living Blind, we explore the perspectives and lived experiences of people with sight loss, and delve into barriers, challenges and real-life strategies for living life to the fullest. Today I'm joined by the Chair of the Board of Directors here at BALANCE, Keith Gordon. And in light of Vision Health Month, we thought it would be a good time to have a conversation all about Charles Bonnet syndrome. Nearly one in five people who experience vision loss have Charles Bonnet syndrome, yet it remains largely unknown, undiagnosed, or diagnosed incorrectly. We discussed what it is, what it isn't... and offer advice for both the general public and the medical community on how to address this condition and deal with it appropriately.

Naomi: A bit about Keith. Doctor Keith Gordon is currently the senior research officer of the Canadian Council of the Blind... or CCB. He was vice president of research of the Canadian National Institute for the Blind from 2007 to 2017, where he was responsible for directing all research activities of the organization.

Prior to that, Keith spent more than 30 years in the ophthalmic industry where he was responsible for a wide range of research and scientific activities.

He is a past research director of blind and Low Vision New Zealand and has been a board member of and worked with a number of national and international organizations associated with vision.

Doctor Gordon's primary research interests lie in the area of ophthalmic epidemiology. He is an adjunct professor in the Department of Ophthalmology and Vision Sciences at the University of Toronto.

Welcome to the show Keith.

Keith: Thank you very much Naomi, it's lovely to be here.

Naomi: And it's lovely to have you. So, I'm going to start with the big question that I think the listeners would probably need to know which is what is Charles Bonnet syndrome?

Keith: Okay, Charles Bonnet syndrome is a condition that's experienced by about one in five people who lose vision. The condition is one of having people experience visual hallucinations. They see things that, that aren't there. They generally know that they're not wrong, but they are sometimes quite bizarre. And it's, it's, it's quite an amazing condition because it's one that's been known about for over 250 years. And yet most people are not aware that it happens, and when it occurs to them, it can be quite frightening.

Naomi: Can you provide some examples of things that people see or, or experience during the hallucinations?

Keith: Yes I can. I've, I've talked to over the years to, to quite a few people about their experiences, and generally they're a little reluctant to talk about it because it sounds like they're going crazy and they very often they think they're going crazy, but they're not. It's not a mental condition. I talked to a woman once who used to see little men on the end of her bed every night when she went to bed. Didn't happen for long, but she'd see these, these little characters appear on the end of her bed. Then I once talked to a man who talked to him over a period of a year or so. And when I first talked to him he had just seen women in red dresses sweeping the floor in his living room. That went on from there to another time he saw the cloakroom tickets. When you check your your coat at an event they give you a little ticket. So he saw all over the walls and the and the ceiling of his room he would see these cloakroom tickets. And I think the last time I talked to him he had woken up in that that morning and he saw a man with a beard in bed with him. So it it can take these hallucinations can take some a lot of very strange forms. And within one person you can see it goes everything from a woman sweeping, sweeping a floor, to cloakroom tickets on the, on the roof, on the ceiling. Yeah, so it's, it's odd. People realize it's odd and, and... and very often they they're afraid to tell people about it because they don't want anybody to think they're going crazy. If somebody came up to you and said, hey, I saw the little men in the in the end of my bed this morning you know. You would think that's pretty strange. And if you don't mind, I'm can I go on and tell you a story. Because actually these are little men with umbrellas this woman said. So one day I was being interviewed by the Toronto Star, about Charles Bonnet and I told this woman about this woman who experienced. I told the interviewer about the woman who experienced. Little man with umbrellas at the end of a bed. And she went away and started writing an article, and her sub editor was looking over her shoulder and since reading what she was writing and he, he said, "little men with umbrellas, he said that's what I have that's a that's what I see". And he subsequently wrote an online article about his experience. He had... he had gone blind in one eye and he was seeing little men with umbrella, so I don't know that everybody sees little men with umbrellas but, but there, there is a commonality. And one of the commonality is actually is that people tend to see they quite often see little people little things. It's called "Lilliputianism", named after "Gulliver's Travels" in Lilliput. But these

little people, not everybody sees little people, but it is it is one of the facets of, of Charles Bonnet syndrome.

Naomi: So it's not necessarily what people see aren't necessarily related to something from their life experiences. In fact, it sounds like it can be quite out of the blue, what they see.

Keith: You know it's it's it's... this hasn't been adequately studied from a uh, brain perspective. It appears that one has to have had vision. Generally people who go blind from birth or early on in life don't experience hallucinations. So there's some feeling that there there is a memory component the the neural experts at this say that they don't think it is a memory thing. But it's it's hard to believe that it that that that the brain isn't remembering in one way or another something that it's seen. There have been one or two cases in my literature of children that have experienced Charles Bonnet, so it's It's very very rare in children. So it is somewhat a life experience. Did this man have to had seen a lot of cloakroom tickets in order to see them on the ceiling? I don't know, but there is some connection between your experience and your your visual experience and what you see after you lose your vision. The analogy that's usually made with Charles Bonnet syndrome, it it they make analogy with people who have a phantom limb syndrome where they lose a limb and then still feel that you know they no longer have a hand or fingers, but they still feel that they can feel their hand in fingers even though there's nothing there. And this is regarded as the the the brain equivalent of, or the ocular equivalent of losing a limb.

Naomi: Almost you know, as if the brain is losing some information that it used to have, and it's trying to fill in the blanks essentially.

Keith: Yeah, that's that's, that's a very good analogy then. You know there a lot of people experience some sort of patterns and and that to me is a little bit like the brain has some, some sort of background noise going. One which is usually overridden by what it sees, which is stronger than the background noise. And when you stop the the seeing things in the front, maybe the brain is it's the background noise that you've seen, so but there's there's very little work that's been done in that area.

Naomi: The brain is, I would agree, definitely an area of an undiscovered country. There's a lot of research that I think is yet to be done, and it's great though I think it's important, and I'm sure you would agree, to research Charles Bonnet syndrome. Uhm, because like you said, a lot of people aren't aware of the condition, and I think if we understand more about it, uhm, you know whether or not there's a treatment or not, we can understand at least the mechanisms and help people who have it. You know, understand a little better of oh why is this happening to me and you know, is this something to be concerned about? So I guess what I'd like to ask is, in your experience, have you seem to have talked to a few people who have Charles Bonnet Syndrome, and you said you know, people are sometimes embarrassed or feel as if they should probably not tell other people. Have you found that they... well, what have people's reactions have been? Are people distressed by them? Do they kind of learn to live with them? What, how... how do people cope with this condition?

Keith: Well, we, we did a little bit of research at a few years ago when we the first study we did and then we go back and talk about the history of the research that I've been involved with. It hasn't been from within, it's been if you like a lot of it has been how, to look at how people are feeling. And I'm an epidemiologist, so the first thing I did was to look at the, the prevalence of this condition in the general population. So initially we did a study where we looked at about 2600 people who were coming to the

CNIB for, for vision rehabilitation, people who had had vision before and we're coming to CNIB to get rehabilitated for the lost vision and they found there that about one in five of people had the condition. And the number was about one in five, irrespective of the cause of the vision loss. So people who had glaucoma, they were about one in five, or people with glaucoma. And people with retinal diseases and people with diabetic retinopathy. All three conditions about one in five people had the condition. So, I guess the first thing to know is that it's not the disease that's causing the condition. It's the vision loss, so it doesn't matter how you lose your vision, you have the potential to develop Charles Bonnet. Not everybody is going to get it. You know four out of five people are not going to get it if you want to look at it from the positive side. But people should be aware that it's a possibility. And we found that doctors knew very little about it. GP's... people go to their GP and say, "hey, I'm seeing things" and the GP's were not aware of it. We did we did a survey of general practitioners and found that about over half had never heard of the condition and about  $\frac{3}{4}$  never really looked at patients in that way. We asked them if they ever told their patients that it was a possibility and they they said no. So there's a, it's a real knowledge gap, yeah and I thank you for, for doing this podcast, because I think hopefully we'll get to spread that knowledge to a few people who aren't aware of it. But then to come back to answer your question, I'm sorry this is a long way to get... your question is, how do people really feel about it? We did... we took some of these two 2500 people and, and asked them, uh, how do they feel about their condition and do they... does it upset them? Does it make them mad? If I tell people what do, how do they feel about telling people and when they tell them, what kind of responses do they get? So to get back to your, your first question is are people upset about it? I think there's a there's a very, very wide spectrum. Some people are OK with it and and others are really put off by it. And I think about a third of the people don't like it. And I think some of the reason they don't like it is that they don't know about it. I think if they were aware of that it happened, they, they would learn to live with it. Now we also asked people how long they they experienced it and mostly it was very short, like a half a minute, or a few minutes a day. It can last for for months. It can last for years. Doctors used to tell patients that are doing it, it won't last for more than a year and a half, and then there was some research done in the UK that showed that there were a lot of people who had it out more than five years. So it it varies. Generally people can live with it if they are aware that that that it's not a mental problem. It's then they're not going. To... People are afraid that they're like they're going to be committed. And I think that that's a valid fear. Everyone said when I published the 1st paper about the prevalence. I had a an ophthalmologist call me, who told me that he had a patient who was committed to a psychiatric ward of a hospital, and the only thing wrong with the patient was that they had lost vision. So so it is an issue. And the medical community and the general community need to be more aware of it. On the side of, you know, do people can people like it? I gave a talk once in in New Zealand to a group of of people who lost vision due to retinal diseases and the woman came up to me afterwards. She said, you know, I see these lovely patterns in front, in front of my my vision quite often. She says I really like it. So you know some people are annoyed by things and others tolerate it, and then others really like it. So you you've got a complete spectrum.

Naomi: That's fascinating to to know. I mean, I guess it's no surprise because everybody is different and the experience is different for everyone. I can imagine that you know, perhaps for some people it would get in the way or be distressing, but sounds like there's some beautiful patterns that come up for others as well. And it's interesting again that I I didn't know that you know, it could be of such short duration, so just a minute or two versus you know, on the other hand some people have the condition for quite a long time or a short time. So there's a lot of variability from what I understand.

Keith: Yes, yes, absolutely.

Naomi: You don't mind me asking. I'd like to take a step back. How did you get interested in researching Charles Bonnet syndrome in the first place?

Keith: No, that's that's a really good question because uh, I I worked for 30 years for a company that made drugs and devices for ophthalmology. Which meant that I attended a lot of meetings of ophthalmology groups and optometry groups. And and I never ever heard of this condition in 30 years. I'd go to ophthalmology conferences and nobody ever mentioned. Then I joined CNIB, Canadian National Institute for the Blind and, and the first meeting I went to when I was there, there was a, uh, low vision ophthalmologist who was something of a specialist in Charles Bonnet gave this talk and she started talking about people seeing little characters on top of their TV and things of that sort, and I said, "well, hold on a second, I've never heard of that kind of thing I've been in this business for 30 years". So I started digging into it and so you know, if that's happening to people, we need to know at CNIB, we need to know how many people are coming to CNIB with this condition, 'cause our staff needs to know how to deal with them. So that's when I did that research that showed that about one in five people had it when they were coming to CNIB before vision rehabilitation. But it was basically that one talk that that got me interested in it, and the fact that I I was I've been around, around the business for a long time and I knew nothing of it.

Naomi: Yeah, no, that's very surprising, but I guess on the other hand, it it isn't in the sense that if you don't mind me sharing, I had a similar experience of working with someone prior to knowing what Charles Bonnet syndrome is and you know having to discover the condition through you know, other folks at BALANCE for Blind Adults who were aware. So you know, this individual was seeing witches, and you know, as a person who you know as an Occupational Therapist, my mind goes to like to your point schizophrenia or another condition that might be causing hallucinations. And I think you've talked about how troubling that can be because people will not get the help that they necessarily need. They'll be, you know institutionalized or they go through the mental health system, whereas that's not necessarily an appropriate treatment for the condition. So I'm happy to hear that you were able to be introduced to it. It's a shame it was a little bit later. But you know, you certainly taken it from here and continued to raise awareness. And you know that story and the stories that you told is just served to demonstrate why it's so important to continue to raise awareness, not just in the community, that certainly is helpful, but also to people who are helping folks with visual impairments and just, you know, doctors and other professionals more widely.

Keith: Absolutely, but as you said that I, I think I it's worth making the point that that you one should not dismiss because you because one has lost vision and is having hallucinations, one should get checked out. You want to not dismiss the possibility of there being another underlying condition. So that should be everybody should rule that out. But there are conditions such as there's certain drugs that cause hallucinations. There's certain conditions like Parkinson's disease can cause hallucinations, so one needs to go to one's General Practitioner or a neurologist and get those things ruled out. You know, on the one hand, you shouldn't be afraid of them, but get them ruled out and then you can say, "oh, it's just it's just my Charles Bonnet".

Naomi: Yeah, and I think that's an important thing to keep in mind is, you know we talked about people being afraid of being crazy, you know, but that's having hallucinations are it's just the thing that happens. I think that you know, as you've mentioned, Keith, if they bother you, certainly seek help. Or if

you want to know what's going on, absolutely talk to your General Practitioner, but I do think that it's important to destigmatize that experience because that's keeping people from getting help I think, right? Like knowing that fear of being labeled as crazy or, or something like that.

Keith: Absolutely, you know, I'm full of these stories. I've that I've collected over the years, but they're all anecdotal, but they they all add up to the same, same situation and I I had a, uh, a woman call me one day and she said "I'm seeing these things and I called my ophthalmologist and told him that I I thought I was going crazy and he agreed". To the Ophthalmologist's credit, he referred her to a neurologist, so so he didn't didn't do it out of hand, but we shouldn't, shouldn't have people automatically saying, "oh yeah, you know you're crazy, forget about it" You know, so not everybody like that I would say that most Ophthalmologists and optometrists are fully aware of the condition. Now we did another little research where we asked retina specialists. Retina specialists see a number of people every day who have lost vision. And we asked them if when they had somebody in their office who had just lost vision, do they tell them about the possibility of developing Charles Bonnet? And and more than half of the of the responders said that they didn't. That that means that you know people are being sent away from the office. They're losing vision and then they start seeing things and the doctors never told them that that could happen, and I think it's it's really important that that doctors at all levels are aware that that's a possibility. And if they know somebody is losing vision, tell them that it's a possibility. You don't need to lie in bed worrying about it. If it happens, it happens and it's not going to do any harm to you. But you you can live with that and it eventually it'll go away.

Naomi: Especially since it's one in five, is the prevalence. That's quite a quite a lot of people and...

Keith: One in five people losing vision, not one in five in the population.

Naomi: So out of yes. So out of out of people who are losing their vision or perhaps have lost some the prevalence of Charles Bonnet is one in five. But you know that all the people coming into a low vision ophthalmologist, its quite likely, you know it's not an insignificant number, so I I agree that it is surprising that a lot of Ophthalmologists wouldn't provide that information. But you know... Are there resources that doctors or other practitioners can access if they want to either learn more or provide that information to their patients?

Keith: There are a couple of websites. There's an organization in Australia called the Charles Bonnet Foundation that has a fairly good website. The the the RNIB in the UK has a pretty good Charles Bonnet segment on their website and there's a new Charles Bonnet Foundation in in the UK that I don't remember the name of but they have provided information. There's one thing I'd like to address if I may. People always ask, ask, you know, is Is there a way that that that can be treated? And the answer is generally no, but there are some things that you can do. So the first thing I think one can do is make sure you get your eyes properly checked. So if you you know, obviously you've got on ophthamologist and you've lost vision, then you probably have have had it checked, but there are people who who haven't had their their spectacles corrected for for a while. And if you get your your eyeglasses checked, sometimes just can make enough difference that that your hallucinations might stop. The other thing is sometimes if one's vision loss is due to cataracts very often, the cataract surgery improves your vision enough that the hallucinations are going to go away. So make sure that you're in touch with your your optometrist and ophthalmologist to get the latest on the status of your eyes. Then there are things that that people try. People try blinking and people try and look looking up and looking sideways and as an Occupational Therapist, I'm sure you you know you know more of these than I do, but the the whole lot

of things. People say if your hallucinations usually happen when you're sitting down, then stand up. If they happen when they stand up then sit down. So just change your environment. People find if you put on music sometimes that that helps. It just interrupts the environment. So try a lot of different things. Some of them work, some of them don't. And the most important thing, I think that an individual can do is talk to people. Talk to others that that have that have experienced the condition and find out what they've gone through. And and talk to your family and friends and tell them about it. And if they laugh, give them hell! It's not a laughing matter and something that people need to become aware of and and become accepting of.

Naomi: I feel like you've provided listeners or you know people who may be wondering to themselves... "oh, I Maybe I should I ought to get this checked out". Or you know, I think you've provided a lot of information for people to get started. What advice would you have for you know folks like me, Occupational Therapists, doctors or people who who Independent Living Skills instructors, people who work with people who have lost or losing their sight? Do you have any advice for them or for me about how to approach the subject or how to work with somebody with this syndrome?

Keith: Yeah, if I can go back at one time, the people who who did vision rehabilitation were told "don't don't talk to people about Charles Bonnet, you're not, uh, you're not a psychologist or a neurologist... you don't have the ability". And I think that's totally wrong and at at CNIB we we changed that. It's important for people to talk and to listen. So as a as a vision rehab instructor, I think first of all, people should be reassured. This is not a mental thing. It's got nothing to do with with your age. It's got nothing to do with dementia. People who who have dementia do get visual hallucinations or can get visual hallucinations, but they're different... visual hallucinations from other conditions. Often people are a bit of afraid of... they, they interact with them. If somebody is interacting with a hallucination, it's not Charles Bonnet. People who have Charles, but I know that that it is not real. In fact, I had a GP called me up once who had a patient and we had a whole discussion. And in between us we came to the conclusion that this person didn't have Charles Bonnet and needed to be seen for something else because the person was interacting with their with their hallucination. It shouldn't cause paranoia. So that's the first thing. Give him some reassurance as a vision rehab worker and and just let them talk and tell them that It's it's normal that it is something that people who have vision loss experience. And if they want to... if you're a Vision Rehab Instructor, you probably know other people with the condition. See if they will talk to each other because reassurance from others is really helpful.

Naomi: That is very helpful to know. I think that the biggest take home is don't be afraid to talk about it. You know, don't be afraid if you are experiencing visual hallucinations, don't be afraid to bring that up to a doctor or even your loved ones. You know whether that's a bit of tough love or not. And then you know, talk as a if you're helping somebody with a visual impairment who might have brought that up to you, I think. It's OK to talk about it. It's ok to reassure a person that this is a common experience, and it doesn't mean that they're, you know in need of mental health services. But you know it's something that can come with vision loss. And it's something that can be lived with.

Keith: Very much so. As as you were talking. I was just thinking that if if one is an Orientation and Mobility Instructor, one needs to be aware whether the the person is experiencing things very often. Not very often. It has happened, if people step into into the street and they think that there's something in the middle of the street. The cars coming at them or there's a, I don't know, whatever bicycle or somebody there. So in order to facilitate things for people walking along the sidewalk or crossing roads, I I think it's

important to understand that people might get a shock from a sudden a sudden thing happening. Uh, I had a friend in the in the UK who he was a retired General practitioner who had macular degeneration and he told me the story about how he got driving in the car with his wife. And on several occasions he would grab her by the arm and say stop. She said why? He said there's A tree in the middle of the road. One has to be aware of these possibilities and. See looking at how that might affect somebody.

Naomi: Right, absolutely? I mean, that's that. that's a real safety concern. If you're doing oriented orientation and mobility instruction, and there's a tree on in the. Middle of the crosswalk. That can be a bit of a shock if you're not expecting that, or at least not letting your instructor know, will help that both of you kind of learn how to how to manage that when it comes up.

Keith: Yeah, it's very rare, but it should be something that they should be aware of.

Naomi: For sure. You know one thing that I'm curious to know. Keith is, you've already done some research. In particular, I think it sounds like sharing. Asking people to share their experiences of the condition and the reaction to it. What are the next steps in terms of advancing research about Charles Bonnet syndrome?

Keith: I, I think it's really important that there be more work done at the at the level of the brain. As as far as I'm aware, there's only one researcher that's already doing this. It's a a man in London, London, England. Who's a neuro neuropsychiatrist who he's done some some really fascinating stuff where he's I, I don't know how he how he's done it, but he he would take people who are hallucinating and and put them in and a do a functional MRI on their brain. And he's shown that if you're hallucinateing a particular color or a particular thing, the part of the brain that deals with that particular facet would light up. So let's say you hallucinated that there were orange things in the room. There's a, there's an area in the visual cortex of the brain that lights up that is responsible for the color orange and that would light up. So he's done quite a bit of work in that area. He's continuing to work in that area, but I think there needs to be a lot more people doing that kind of research. There's also a the auditory equivalent of Charles Bonnet, where people hear things it's got nothing to do with each other, but people who've lost hearing can also have auditor... is that the term... auditory hallucinations. And so these to me are pathways to understanding that the brain better. And I just think that there needs to be more neurologists and and neuroscientists looking at the brain looking at Charles Bonnet in the brain. Another aspect that I would like to see is people looking at possible medications that could be used to treat the more severe cases and for people who are enjoying their patterns, that's fine that they don't need treatment, but there are people who who are a bit upset about having it and could you deal with the treatment. They have been researched where they've taken various psychotropic drugs and treated people and found, you know one very odd case that would improve, but there's, there's been nothing that's really being worked on a on a on a general basis. So it would be nice to see somebody study that in more depth. So number one. I'd like to see study a more more study within the brain. Number two I'd like to see a study of medication.

Naomi: Yeah, absolutely. Those are great future directions. Alright, well is there anything else that we didn't talk about today that you feel like it would be important for people at home listening to know about Charles Bonnet syndrome?



Keith: No, I don't think so. I just, I think we've pretty well covered it. You know, as you said, the big take away is to talk about it and be reassured that it's, it's normal it happens to a lot of people who have vision loss.

Naomi: Alright, well thanks very much for coming on the show Keith. We really appreciated your insights and all the information that I'm sure will be helpful for for either people Listening with vision loss or the people in their in their lives.

Keith: Thank you very much and thanks for giving me this opportunity.

Naomi: That's it for this episode. Thanks for tuning in. I really hope that you enjoyed this interview with Keith Gordon as much as I enjoyed doing it for you. For more information about Charles Bonnet syndrome, check out the links in the description below. Special thanks to Doctor Keith Gordon, our producer, Jeffrey Rainey, executive producer Deborah Gold. And the entire team at BALANCE for Blind Adults. If you liked what you heard today, feel free to subscribe or follow us on whatever platform you're listening on. And don't forget to let us know how we're doing! We're on Facebook, Instagram, YouTube and Twitter at BALANCE for Blind Adults. You can also email the podcast with any comments questions or suggestions you may have at [LivingBlindPodcast@BalanceFBA.org](mailto:LivingBlindPodcast@BalanceFBA.org). For more information about BALANCE for Blind Adults and our programs and services, or to access the show notes or the transcription of this episode, please visit us at [www.balancefba.org](http://www.balancefba.org). I'm Naomi Hazlett, and this has been living blind. Thanks for listening.

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