Hadley

My phantom vision

Presented by Douglas Walker

**Carmel:** I was losing slowly my vision. I thought perhaps my brain was just doing what their non-existent limb seemed to be doing.

**Marc:** This is Hadley’s Insights and Sound Bites, where people facing vision loss share what has helped them cope and adjust.

**Carmel:** My name is Carmel Anderson from Chicago, Illinois. It's early morning in Chicago, and I just listened to one of the podcast about Charles Bonnet syndrome.

I have lived at supported living places I lived with multiple disabled people, a couple of whom had or were all amputees. I had heard the stories of many amputees who would at times at the 20 years of not having a limb reach down to scratch, a thought that hadn't been there for 20 years.

I never had Charles Bonnet Syndrome at any time or noticed it intermingled within the vision that I had until I got and was diagnosed on the level of severe glaucoma.

I asked myself, is that what's happening to me? And my theory was because I was losing slowly my vision, and it will one day be completely gone. I thought perhaps my brain was just doing what their non-existent limb seemed to be doing.

I called it phantom vision. And this this is the first time I've ever known that it had a proper name, that it was a legitimate syndrome and a condition amongst visually impaired people.

But it seemed to me to make so much sense, and I would never have made that connection if I hadn't had the joy of seeing the courage of multiple disabled young adults. Thank you for letting me hear what I know as Charles Bonnet Syndrome, but which I will always fondly identify as my phantom vision.

**Marc**: You never know who might need to hear your story. If you’d like to share with us, just leave us a message on our Insights & Sound Bites voicemail. By calling, 847-512-4867. Or, you can use your smartphone or computer and email us a recording to podcast@HadleyHelps.org.