

Pigeonhole Episode 41

[bright ambient music]

Introduction

CHORUS OF VOICES: Pigeonholed, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole, pigeonhole. [music dissolves into chill melody]

CHERYL NARRATING: I recently came across a 2021 paper called "Visual Disturbances: What Are They? (& What To Do)." I didn't click on it. Disturbances! And that is the end of the medical portion of today's show. Not everyone wants to do something about these, unless by "do something," you mean tell your friends. I wanted very much to tell Carmen Papalia about the "disturbances" I see because he sees something kind of similar.

CARMEN: My relationship to them has really changed over the years. I really kind of just started thinking about what they are and like how I would categorize them and like started talking about them with other people more recently. [chill melody fades out]

My name's Carmen Papalia, and I'm a non-visual social practice artist with chronic and episodic pain. I'm calling in from a camper in rural Ohio. This is the stolen land of the Hopewell Culture and Myaamia nation. That's M Y A A M I A.

Non-visual and extra-visual

CHERYL NARRATING: And by "non-visual," he means....

CARMEN: I don't use vision as my central reference point. At a point in time, I had to shift value from the visual to the non-visual as a way of like, you know, navigating my surroundings. I also feel like I privilege the non-visual senses as a way to connect with other people as well.

CHERYL NARRATING: So, like music and sounds and touch. And he recently started connecting by sharing what he calls "extra-visual," images the brain produces without the eyes having to see anything.

CARMEN: Yeah, I always have enjoyed watching them, and you know, I've never really thought they were a disruption or an obstruction in my visual field. You know, the perception is that blindness is, you know, people are experiencing total, total blackness or darkness, which isn't the case. Like, you know, not [chuckles], not many of us who are on that spectrum of experience have complete blindness, for one. I love this experience as a counterpoint to that.

CHERYL NARRATING: And these extra-visuals are something a lot of people experience, very specific types of hallucinations, an absolute feast for the senses. My friend Grant called them "playful apparitions." [slow build-up of a cacophony of water bubbling, static crackling, and ambient music with a slow beat]

CARMEN: I describe them sometimes as like they move like jellyfish. There are different layers to them too. So, like there is this more kind of like water displacement layer that is kind of wavy and shimmery, and on top of that are more kind of like visual objects that are floating around and swimming across that field of water displacement. Yeah, and then there's patterns too. So, there's like this, this radar sweep almost that kind of displaces all of the colors and shapes as it

kind of waves through. And sometimes it kind of takes on this quality of a light kind of or like a bright color that's sweeping across. [bubbling water, static, and ambient music slowly fade out]

Sometimes they like, take on this like clockwise formation and just lightly, you know, this watery kind of hallucination, it'll follow a clockwise movement around my visual field, and then these other lights will just swim on top of them. A more like infrequent visitor for me is this the spiral. I used to think that it was more like a pinwheel with like the arms of a fan or something or a windmill, but I started talking about it more to some friends who also have these hallucinations. And I just started watching it more. It doesn't really have arms like a fan. It's more like the drawing of a spiral, and it just spins, and the tail of it whips around at a different rate than the center does.

CHERYL: Ugh! This sounds so delightful!

CARMEN: [laughs]

CHERYL: I wanna get in your head and watch this.

BOTH: [laugh]

CHERYL: Wow!

CARMEN: It is. It's pretty magnificent. Like, I don't even know how to describe it sometimes. These are I mean, pretty dynamic. Sometimes I've described it as like a animated oil painting from space, like.

CHERYL: Ugh!

BOTH: [laugh]

CHERYL: So textural! Oh my gosh.

CARMEN: Mhmm. I think I just at some point decided or accepted that vision wasn't my central reference point. Although this is like a very visual experience, I guess I didn't expect that my vision would be usable to me. So, I really put [giggles] all my eggs in a basket of I'm a non-visual artist; I'm a non-visual learner. And so, when I did encounter these hallucinations, they were just part of my non-visual experience. That's how I understood them.

CHERYL NARRATING: And Carmen wants his community to understand them too, like not just understand them in our minds, but also in our bodies. Carmen led an embodiment warm-up for this online study group called Dis/Rep, short for Disability Representation. The embodiment warm-ups were something to help us mark that we'd be spending this time together, something to get us moving or being still or thinking or breathing or feeling. In Carmen's case, maybe a little something to inspire visions like jellyfish.

Dis/Rep embodiment warm-up

LUTICHA: This is Luticha speaking. We're going to now enjoy and embodiment warm-up to start us off led by non-visual learner and artist Carmen Papalia.

CHERYL NARRATING: Carmen talked about whose lands he was calling in from that day, and since we were on video, he gave a self-description of what he looks like and his lovely summer

outfit before leading us into a story about how he'd started noticing shimmering, fuzzy vibrations when he was young. Over time, the vibrations amplified, became more colorful, and turned into playful hallucinations. The embodiment exercise started like this.

CARMEN: I want you to just gently rub your eyeballs with your, if you can, your pointer and thumb or anything, really, where you're just like, you know, kind of exploring the surface area of your eyeball through your eyelid. Yeah. Find a rhythm or some way to rub your eyes so you start, until you start seeing flashes of color. [pause] I just want us to think of how to describe what we're seeing and we're experiencing right now. "Warm circle" I got there in my screen reader. Ah! This is kind of like it's a mixture of underwater and galactic for me right now. And I'm seeing stars. Some shapes emerging for people. That's really nice. Sometimes I see this backwards C shape that's a C shape in light. Mm. "Oil in water. Oil on water at night." That's a very good description. Thank you.

CHERYL NARRATING: That was just a snippet of the playful and dynamic images people shared.

CARMEN: Okay, and I'm gonna stop rubbing my eyes. But [chuckles] to be honest, I don't have to rub my eyes to see these hallucinations. I'm always experiencing them! But yes, if you ever want to return to that space and visit with those playful apparitions, I would invite you to. [laughs] Is that my time, folks? I feel like it's so brief, but I wish I could share more time and space with you today! Okay.

GRANT: Thank you so much for sharing with us.

CARMEN: Thank you!

GRANT: Thank you for the playful apparitions that were here with us today.

CARMEN: [laughs] Awesome. Well, I hope those stay with you, or they go away based on what you want.

CHERYL: I couldn't participate during the activity with rubbing my eyelids because my allergies were so bad. So, I just sat and listened, and I really enjoyed all the positivity and appreciation that you expressed.

Cheryl's friendly visitors

CHERYL NARRATING: But I didn't just go to these workshops. I got to caption the Zoom recordings of them! But something super weird happened when I tried to caption this one.

CHERYL: I couldn't see the captions. And I kept moving around, like looking, trying to get a different angle on my monitor. I just was like, "Where's Carmen? Where are the words? What?!" I kind of focused in and realized the screen had just gone, like, bright white. And I was trying to look through this, like, cloud of light to find you. And then I noticed that I was having a scintillating scotoma, this backward C made out of rotating prisms that was very slowly floating across from left to right.

And I just...I can't tell you how peaceful it was to be literally listening to you talk about how beautiful these things are and totally non-pathologizing and then to be having this thing happen. And I just went to bed [chuckles] and just like blissed out watching. And when it left, I was so sad! [chuckles softly] The first time I had the scintillating scotoma.... And maybe I should just

stop calling it that because first of all, nobody knows what that means. And second of all, why not call it "a friendly visitor?"

CARMEN: Mmhmm, mmhmm.

CHERYL: But it was turrets of a castle. I looked it up online. I'm like "vision rainbow castle turret," and I came across some essay that was written hundreds of years ago. And there was a picture, a painting, and it was exactly what I had seen of this, like a castle turret, but made of rainbows.

CARMEN: Mm.

CHERYL: [giggles] And then the one that I had when I was captioning you, it was the backward letter C, made up of like at least a dozen spinning lines. [laughs] And I was lying in bed like, "Carmen?"

CARMEN: [chuckles]

CHERYL: "Can you telepathically see this? I think you will like this one."

CARMEN: [happy laughing] Now that I'm talking to more people who also share this experience within my community— Like, I'm not gonna have these, like, affirming conversations about this experience with my ophthalmologist. When I was in this process of like my vision was changing, and I was faced with this like, whether to live as someone who still privileged vision or change my life and routines in a way to like kind of embrace the non-visual aspects, I didn't feel like I was leaving anything. Like, I didn't feel like I was grieving my vision loss. I felt like I was entering this, like, vast and vibrant in dimension that I totally wanted to keep exploring. Since I've started talking to other people, some with the same visual condition as I have, you know, I've been able to compare notes, and, you know, I've developed new words for some of the hallucinations that I see.

CHERYL: Ah!

CARMEN: [laughs] This little shape that I see, a backward C, my friend Andy in Chicago, he calls it a Cheeto. And he shared this with me, and now I can't not think of this shape as a Cheeto, you know? But also, my friend Colin, he calls that same shape a glow worm, and he's a fireworks enthusiast. So, it really makes sense given his interests.

CHERYL: You and Andy both have a backward C, and I had a backward C.

CARMEN: [chuckles]

CHERYL: Oh my gosh. I feel like I have like, maybe stepped a toe into this elite circle of awesomeness.

CARMEN: [delighted laugh]

CHERYL: I just remembered something, [laughs] and that is. I started having these amazing hallucinations. They only lasted for a few months. They were so.... I cannot tell you the beauty. Can I tell you my favorite one?

CARMEN: Yeah!

CHERYL: Okay, so I'm lying in bed. I'm awake. And just for context, when I had my brain injury, my mind's eye basically went blank. Like, that stereotype of people with blindness experience of just having like a black void, that is what I was experiencing! [chuckles] And I've gotten a little bit of it back over the years. So, I closed my eyes, and all the sudden, before me was this completely vivid topographical map. And so, I'm just staring at this map and looking at all the rings of elevation. And all the sudden, all of the mountains on this map popped up like a 3-D pop-up card: [voice gets higher and faster] boop, boop, boop, boop, boop, boop, boop, boop!

CARMEN: Mmhmm. [chuckles]

CHERYL: And the layers of the mountains came to life, and they jumped up. It was so gorgeous. And then, like, my whole body shook really hard, and then the map disappeared.

CARMEN: Wow.

CHERYL: And I had another time where ribbons and fireworks in full, vivid color, three-dimensional, were just like bursting onto the screen. And it was so beautiful! And then the shaking and then the vision stopped. And it all went away on its own, very sadly.

CARMEN: Mm! I was like, seeing pretty vibrant colors while you were describing your fireworks too! [laughs]

CHERYL: [gasps] Ooh! And did you see the ribbons?! [laughs]

CARMEN: I didn't see ribbons, but I was I was seeing a lot of, like, color bursts. [laughs] Yeah.

CHERYL: Oh, how beautiful. I'm so glad I could share that with you!

CARMEN: I want more of us to come out of the woodwork, or at least I'm sure there's so many.

Wrap-up

[mellow music fades in]

CHERYL NARRATING: Months ago, when I emailed Carmen to first tell him about my backward C made of prisms, I spotted a call on Facebook by M Leona Godin asking what she calls "blindkind" to share the stuff they see. She combined the responses and short conversations into a blog post called [Colorful Hallucinogenic Pixelated Snow Fuzz & Other Things Blind People See](#).

CARMEN: And this is, I think, what disability culture gives us, is like a space where we can honor those experiences, some of which would maybe be erased or invalidated in a medical setting. And we can give names to those experiences, and we can understand them as valid ways, and not just valid, but like exciting ways of being in the world. Yeah. 'Cause I yeah, I love that in like a crip space or disability-informed space, the norm is a diversity of experiences and identities and learning styles and ways of being all which are connected to, like, forms of knowledge, you know, that we're just uncovering through holding these affirming spaces together. Like, if we're not able to hold that space and understand these experiences as beautiful or valuable and desirable and things that we want to hold on to and make art about,

then they will go away. I mean, we're making space for that preservation of these experiences within disability culture. Let's just keep the conversation going.

[mellow music dissolves into bright ambient theme music]

CHERYL: Every episode is transcribed. Links, guest info, and transcripts are all at WhoAmIToStopIt.com, my disability arts blog. I'm Cheryl, and...

TWO VOICES: this is Pigeonhole.

CHERYL: Pigeonhole: Don't sit where society puts you.