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Episode 98: At the End of Sight Air Date: September 18, 2024

Vox Media | Episode 98 At the End of Sight

ANDREW LELAND:

So I was a teenager, probably, 15 or so. And the movies is a big memory that I have of just a friend popping out of their seat and being like, I'll be right back. I'm going to go grab a drink or go to the bathroom. And I would just think like, Wow. It was like seeing a friend do the pole vault or something, like, how are they doing that? But then there was this cognitive dissonance because I was like, that shouldn't be hard.

PHOEBE JUDGE When writer, Andrew Leland, was a teenager, he started to notice something about his vision.

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(AS

NARRATOR):

ANDREW LELAND:

And it was coming at this time when I was doing-- as a 15-year-old, you're newly independent. And so it wasn't like, oh, these things I've been doing my whole life, now, they feel different. It was like, I'm going out in the woods with my friends at night. And oddly enough, I'm bad at it.

NARRATOR):

PHOEBE JUDGE He remembers, his father bought him a modem. This was in the early '90s. And he would use early search engines to research night blindness. He remembers reading one website that he felt described his situation exactly. Mild night blindness is often ignored by the patients and becomes apparent in the teenage at evening parties. And he read that by middle age, patients experience complete functional blindness.

PHOEBE JUDGE: Were you scared?

ANDREW LELAND:

No. Honestly, I wasn't. I feel like nobody believes me, but the reality was it just felt very distant of the idea that I would even be where I am today, or the eraser size eventuality beyond that, or the final closure of the opening of visual acuity. Eventually, all of that is scary. But I think when I was 17, even after I was diagnosed at around 19, it just didn't feel remotely imminent. It was just like, that's a thing that's going to happen to a guy who will share my name and DNA, but who the heck is that guy in 20 or 30 years?

PHOEBE JUDGE: Because we're like invincible at 15.

ANDREW LELAND:

Exactly. Exactly. It's like realizing that you're going to die someday. It's like, sure, that's going to happen, but what possible relevance does it have to the CDs that I'm browsing at borders books and music at the moment?

PHOEBE JUDGE Andrew Leland has retinitis pigmentosa or RP, a degenerative eye disease.

(AS

NARRATOR):

ANDREW LELAND:

And it works from the outside in. It's the rod cells and the retina that die first. And those account for peripheral vision and night vision. So I have terrible low light vision. As soon as I enter a dim restaurant, I'm basically blind, totally blind.

And then I just have a very, very narrow field of vision. But within that narrow field, my acuity is good. So if I'm sitting at my desk right now, and wherever I choose to look, I can see the thing. It's just that I am seeing a very small amount of the thing compared to what you are probably used to.

So there's a logo on this speaker that I have on my desk. And when I look at it, I don't see anything of the speaker. I just see the little inch of the logo. So it's probably like looking through a toilet paper tube.

PHOEBE JUDGE And he says that that toilet paper tube, his field of vision, will most likely keep getting narrower.

(AS

NARRATOR):

ANDREW LELAND:

The thing about this disease that doesn't have a cure is that it's progressive, and it might be super, super slow, or it might be fast, but it's moving. So I don't know when that moment comes, but certainly, that hole is indeed,

shrinking.

PHOEBE JUDGE He remembers the day he got his official diagnosis. The doctor asked, can you see stars? It made everything real for his mother, who sat up straight and said, you can't see stars.

NARRATOR):

Through his 20s, Andrew Leland says he didn't notice much of a change. He'd stay in his seat until the credits ended after a movie, playing tennis got harder. He met a woman named Lily.

One day, when they were hiking with their dog, he knelt down and said to the dog, oh, no, what have you eaten? And then when Lily turned around to see if the dog was OK, he proposed.

As they walked back to the car, he said, you remember I'm going blind, right? He says he was kidding and not kidding. He stopped driving later that year. They had a baby.

When their son got older, Andrew Leland talked to him about blindness. He'd say, I have bad peepers. He started to carry a cane.

PHOEBE JUDGE: You resisted the cane for a while.

ANDREW LELAND:

Oh, yeah. I've heard stories about parents who don't want their kids to learn Braille because when they see them, it's just like this trapping of blindness. And I've never really gotten that.

But the cane, I would say, above anything else, is just like the stigmatized symbol of blindness, where it just instantly changes how people look at you. People think you have no vision, whatsoever. They treat you differently. And it's true on the most intimate level, too. It's not just strangers. It's like your intimates, your friends and family are all thrown for a loop by the cane.

PHOEBE JUDGE He remembers the first time he used the cane in front of his wife, Lily.

(AS

NARRATOR):

ANDREW

That was in a restaurant.

LELAND:

PHOEBE JUDGE In Greenpoint, Brooklyn. He says it was a fashionable restaurant, quote, "Which means it was lit by a single (AS Edison bulb running at half power."

NARRATOR):

ANDREW LELAND:

And I had a cane that was foldable. And I just kept it in my bag, always. I never brought it out unless I was alone in a foreign city, going to a dark bar or a restaurant. I was just like, this is going to save me from knocking a beer onto somebody, which I definitely have done several times.

And she had never seen me with it. I think she knew I owned it, but it was just like in case of emergency or something. And I was like, oh, God, this restaurant is so dark. Finding the bathroom is going to be so hard. I'm just going to bust it out.

I never had any cane training or anything. I just did it. And she saw it and was like, what do you need that for?

Put that away. And it was fraught for me because it was like a risk for me to bring it out, and it was hard for me.

And then to have her have that reaction, I think, felt like it confirmed my worst fears. I look vulnerable. She doesn't like the way this looks.

And I hadn't been remotely open with her about my anxieties and fears about the cane. It was really, I was just like, bought this thing, in my best Norm MacDonald impersonation voice. And I didn't share with her the pain, and the weirdness, and the anxiety around that, and so she didn't know to have any of that.

And it was just like, I had it thrust into her face. And she had her kneejerk reaction to it. So that was the beginning of that conversation that lasted for a long time afterwards. And now, things are much, much different.

PHOEBE JUDGE Today, he uses his cane everywhere he goes.

(AS

NARRATOR):

ANDREW LELAND:

The power of the cane can't be overstated. It is so useful every single day. And the ways that it's useful arefirst, I would say, just as a signal. The same thing that made it painful and difficult to bring out, it made people see me differently.

We recently went on a family vacation to Europe, where we went to some pretty crowded spots. And Lily remarked on just how useful it was, even just for her, because a lot of people joke that it's like Moses parting the Red Sea. They just see the white cane, and the tourists and everybody, they just perl out of the way.

But that's really helpful for me. It means I'm not constantly bumping into people or apologizing. It clears a path just through its sheer psychic force that emanates out of it. And then, of course, there's the physical part of it, where those objects that don't know to clear out of the way, like animals or fire hydrants, or curbs, steps, all of these things would be very painful for me to encounter without knowing about them.

And I think the one way to think about it is like if you're looking through 6% of what a fully sighted person sees, the cane is just a little bit of a prosthetic to help you reach some of those obstacles that your eyes are no longer touching.

PHOEBE JUDGE He's written a book, *The Country of the Blind-- A Memoir at the End of Sight.* It's dedicated to his wife, Lily, and to their son. The book is about a lot of things, more than we could touch on in this conversation. The history of NARRATOR):

Braille, assistive technologies, writers like James Joyce and Jorge Luis Borges.

It's also about Andrew Leland's marriage and all of the ways that his wife does little things for him, like keeping her shoes off the staircase, and putting food in the refrigerator in a specific way. He writes, these are all acts of love. And love, by its very definition, always entails a surrender of independence.

I'm Phoebe Judge. And This Is Love.

[MUSIC PLAYING]

We'll be right back.

In his book, The Country of the Blind, Andrew Leland writes about walking in New York City, with his cane, and making eye contact with a man leaning against a deli. He writes, "I looked away. And he said the thing that I've read on so many strangers faces since I started using the cane, You can see." He spoke in the sneering voice you'd use to say, give me an F-ing break.

Andrew Leland writes that he's had quote, "Periodic desire for the eye disease to just get it over with and take the rest of my sight. I wanted to be relieved of seeing the way people looked at blindness-- the scorn, the condescension, skepticism, pity, revulsion."

In 2018, he decided to attend the National Federation of the Blind's convention in Orlando.

ANDREW I FI AND:

And the thing everybody said to me is like, it's going to change your life. I don't care if you like the NFB. There's a controversial, sometimes, divisive group. None of that matters. Just going to that convention, it's going to blow your mind and change your life. And it took me like literally 11 seconds to know what they meant. I walked through the sliding glass doors and was just completely overwhelmed, because you walk into this convention center, and there's 3,000 blind people there for the convention.

And so just immediately, you see, probably, two or three dozen blind people. And if you're totally blind, you hear just the clatter of canes and people gently colliding with their canes. And I saw a blind kid with a cane-- I'd never seen a cane that tiny. And he was asleep in his mom's arms. And his cane was dragging.

And a guide dog had an accident. And there was a hotel employee, guarding the accident to make sure nobody plowed into it. And I was like, oh, OK, I've arrived. This is it.

And it was actually a really emotional for me, too, because I think, I was coming from that place of like, do I deserve this cane? And like, I'm the only person I know going through this experience. And suddenly, it was like, welcome. There was this first person plural experience, where I was like, oh, I am part of a group.

And yeah, so that was my initial reaction. And then it just deepened and extended as I met people and attended the Braille Book Fair and met people from all over the world, and really interesting people, and really sad people, and everything in between.

PHOEBE JUDGE: I mean, it seems like such a contrast to some-- you go into this convention, and it's just like, I don't have to worry for a second about this one aspect. It's a place of refuge. And throughout the book, you talk about the ways in which the word "Blind" is used negatively for so many different things. And then you talk about this kind of wild ice bucket challenge. Will you just subscribe this blindness challenge and what happened?

ANDREW LELAND:

Yeah. One of the biggest funders of research to find cures for diseases like mine that don't have cures is the Foundation Fighting Blindness. And they got in trouble with the National Federation of the blind a couple of years back for this fundraising viral campaign that they did, called the How I See It challenge, piggybacking on the ALS Ice Bucket Challenge, which was super viral. And everybody from Obama to Bill Gates to Kermit the Frog dumped in a bucket of ice water over their heads and recorded a video of themselves saying, I challenge you to raise money for ALS.

And the idea with the Foundation Fighting Blindness, FFB campaign, was to put on a pair of sleep shades that totally block out the light. And then do some daily activities of your life, like clean your kitchen, or fry an egg, or even there was some that was like, take care of your toddler or something.

And these videos were sighted people putting on sleep shades and then being like, whoa, OK, how am I going to do this? This is so hard. Wow. And the whole point of it was like, see how hard and impossible doing pretty much anything as a blind person is? Please give us money so we can end blindness.

And the problem with that is, as the NFB pointed out, primarily, blindness is not the experience of being a sighted person and sticking a pair of sleep shades on, and being like, whoa, how am I going to do this? I mean, sure, if you are suddenly blinded in a car accident, which I hope, does not happen to anyone, but the reality of the world is there are wars, there are car accidents, people are blinded every day, yeah, the beginning of blindness is going to be scary and hard like that.

But if you're talking about somebody who is a blind person, who lives with it day in and day out for a day, a week, a month, a year, that's no longer the experience. There's no longer that, whoa, whoa, that is exacerbated by something like the How I See It challenge.

And so it really, it plays into the stereotype that you feel as a blind person every day on the street, because somebody sees you walk up to a gate at an airport. Never mind how you made it from your bed all the way to the airport, all the way to the gate on your own, but as soon as they see you, they're like, sir, there's a trash can in front of you about three feet, but then a little 12 degrees off to your right, trash can. And you're like, do you think I just landed here from another planet? How did I do anything? How do you think my shoes got tied? That kind of perception of blind people that is so pervasive is exacerbated by stuff like that How I See It challenge.

PHOEBE JUDGE: And does that happen to you on a regular basis, that people act as though your savior has arrived because they're going to try to help?

ANDREW

LELAND:

I'm weird because I do have a fair amount of residual vision. I feel like I can skirt a lot of it, because people will be about to do it, and then they'll be like, he seems like he can see something, or I'll just like steer around the obstacle myself, and they're like, he's OK.

But my friends who are totally blind or who have less vision than I do, I feel like they get it more. And the more vision I lose, the more it happens to me. But it certainly happens to me.

The other day, I was visiting Portland, Oregon. And I was in a coffee shop I'd never been to. And I was like, well, there's only one place the bathroom could be. It's got to be in this back room, because this is just one big room.

So I went into the back room. And I heard a voice saying like, you need any help? And I just was like, I don't know if he's talking to me, I'm just going to ignore him. It was not very well lit. I couldn't really see, but I just started exploring with my cane, which is what you do.

And then all of a sudden, I feel a hand on my elbow. And he's like, this guy accosted me. And I was like, I shrugged him off. I didn't want to be touched in that moment. And he was like, do you need help? I was like, no, I'm just finding the bathroom. And he's like, well, you were going to knock something over. And I looked, and it was like there was a bookshelf that had toilet paper on it, like extra napkins or something.

And it was as though there was like a pyramid of champagne flutes or something that I was going to knock over. But he just saw the cane, and saw me. And it was like, clearly, we got a Mr. Magoo situation on our hands, and I've got to intervene. And the reality was, I was making my way over. And I would have found the bathroom in the following eight seconds.

But then the wildest part about it was, as soon as I shrugged him off, he was like, OK, touchy, and was angry that I refused to accept his help. And that is a very common thing, too, is that you'll get the good Samaritan like, let me help you. And when the blind person says, no, I'm good, it's like, well, fine. Go suck an egg. And it's confounding.

And the best answer that I've found for that is you're shattering their self-image. They have this image of themselves as being helpful. And when suddenly, they're confronted with the idea that actually, maybe they're being intrusive and touching you without consent, or being condescending, that does not compute. And so then there's this defensive reaction.

NARRATOR):

PHOEBE JUDGE There's a place in Denver called the Colorado Center for the Blind. It's a residential Training Center run by the National Federation of the blind. Andrew Leland visited. He describes it as a place where people, quote, "Learn how to be better at being blind."

ANDREW LELAND:

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It is entirely run by blind people. I think there's maybe like a part-time sighted accountant. And there's a assistant, who doubles as the driver. But it's a blind space on the level of the NFB conventions.

And students go there. And they're adult. I went to the adult program. And there are everybody from newly graduated high school students who are on a gap year to college or wondering if they should apply to college or how they'll deal with college as a blind person to 60 or 70-year-olds. And similarly, it's people who have been blind their entire lives to people who lost their vision, sometimes, as recently as a couple of months prior to arriving at the center. Everything from disease to multiple people I met had gunshot wounds that had blinded them.

And the fact that all the instructors are blind cannot be overstated how important that is. And the philosophy is really like, it's tough love. And they've gotten criticism from people who-- it's not for everybody, but I think for the right kind of blind person, and certainly, for me, I think I was the right kind of person, it's transformative, because it really forces you-- the lesson that you learn is, you can figure it out.

Whether it's Braille class or cane travel class, which is the wildest one, by the way, just being out in Denver traffic with a blind instructor and then two or three other students who are under sleepshades, everybody's under sleepshades, I should mention, from 8:00 AM to 4:00 PM every day, all the students, unless you have a doctor's note saying you have no light perception or completely occluded. It's just the message is, this is not rocket science. Yeah, it's hard. Yeah, it's overwhelming. But look, we can do it, and so can you.

And I went there, thinking that I was going to get tips and tricks, like, put the rubber band around your shampoo to be able to distinguish it from the conditioner. You do pick up things like that, but really, it's the philosophy that sticks with you and just the confidence from getting lost in Denver, under sleepshades, and finding your way back, or cooking a meal and thinking you're going to burn something. But then you figure it out and serve up the meal, and it's great, those kinds of things. Then when I'm in my daily life now, even with more vision, I'm like, this is not so scary. It's totally a hackable problem.

PHOEBE JUDGE: It's like the anti-blindness challenge.

ANDREW LELAND:

Right. Right. I mean, it resembles it because you're putting on sleep shades and trying to do daily tasks, but the message is exactly the opposite. It's like, yeah, you could mind a toddler, and fry an egg, and clean your kitchen. Absolutely. And in order to graduate, you have to pass these series of increasingly difficult tests.

And everybody freaks out when they hear about the final travel test, which is wearing sleepshades. They drive you around in circles, so you have no idea where you are. And then they let you off on some corner in Metro Denver. And they say, OK, find your way back. You're only allowed to ask one person one question. And you only have a flip phone that has the center's number preprogrammed into it. So if you get into trouble, you can call for help, basically, but you can't use GPS or anything.

And people do it. Every week, people do that. It's amazing. And yet, when you find out how they do it, it's like, oh, OK. I guess, that makes sense, which is, I think, a common thread with a lot of these things. People are like, wow, as a blind person, X, Y, or Z. And you're like, well, I crack the egg into the bowl. I can feel both of those things. Right. OK. Not that hard.

PHOEBE JUDGE: When you met your wife, you had more vision than you do now. How much does it play into your relationship?

ANDREW

LELAND:

Yeah. I mean, it's funny. There's a lot of things in my life that I ask myself the question like, is this just how this process works? Or how is blindness a factor here?

And I think, marriage is definitely one of those areas where, sometimes, I can get in my head and be like, this is blindness at play. There's internalized ableism on my part, or she's being ableist without realizing it. And then sometimes, I'll have that thought, and then I'll step back again, and I'll be like, I feel like this is a situation where we're just two people who have been married for 12 years, and that's how things go. And I think, the reality is it's both.

Again, everything I'm about to say, I think, is just like marriage. But in the beginning, I really wasn't comfortable talking about my anxieties around blindness and my needs around blindness, in part, because I didn't know what they were myself. I didn't have a good sense of what I needed.

And so it created conflict because I wasn't talking about it. And then she would encounter these changes, but there wasn't really an explanation for them or there wasn't really like a language around my feelings around them. And so it would just be like, why are you so bad at cleaning the kitchen all of a sudden? I thought you said you were going to clean the kitchen, but half of the counter is filthy. And then I'd be like, I'm going blind. And there would be this melodrama.

But then I would be like, right, maybe I should figure out a way to clean the counter that does not rely on my vision, but instead, run my hands over the counter, which is a surprisingly difficult thing to do. It's not difficult to run your hands over the counter, but it's difficult to retrain my brain.

And also, I think there's still that stigma in my own head, where I'm like, it just must look weird for me to be like groping and all this negative images of blindness that I grew up seeing, whether it's like Mr. Magoo or the horrible Jose Saramago book/movie, whatever you want to point to, it's hard for me to do that. But the work that I do every day, whether it's reading Braille or running my hands over the counter to see if the cutting board is clean is to destigmatize that.

And I think it's the same process in our marriage, where there's new changes as my vision changes. Or like last night, I've been trying to write more Braille using a slate and stylus. And she was like, wow, that really sounds like you're doing something with your mouth, because basically, the way a slate and stylus works, it's like the closest thing to a pen and paper for a blind person. You're basically hand-embossing a page. And it sounds like you're doing something gross with your teeth, like popping something, because it's this little like pop, pop, pop.

And it made me really self-conscious for a second. And I was like, I want to do this every day for the next 10 years to get really good at it. It bums me out if you're going to think this sounds some weird bodily thing. And she was like, no, no, no, it's fine. Don't worry about it. But I think eight years ago, that would have been a more stressful conversation to have.

PHOEBE JUDGE We'll be right back.

(AS

NARRATOR):

[MUSIC PLAYING]

PHOEBE JUDGE: What about your son? Do you talk to him about that at one point, you did see that tree fully, and now, you don't?

And what's his understanding of your vision or blindness or continual progression of this? The

ANDREW

LELAND:

Amazing thing about him is, unlike me and Lily, where we met where blindness wasn't in the equation and it wasn't part of the conversation, he's 11, and it's really like the last 5 to 10 years that I've been really dealing with a lot of this stuff, like starting to use a cane, and writing a book, and dealing with screen readers, and everything. And so it's really his whole conscious life is me engaged with this stuff.

And the incredible thing about that is that it's totally normal to him, as a result. It's all he knows. It's like a part of our life the same way that if I were a botanist, like me tinkering with my plants would be part of his life. And it wouldn't be weird that dad is always talking about plants.

And so he just has a really, I don't know if casual is the right word, but it's just natural, his relationship with disability, with talking about blindness. He has got curiosity about it because he's still young enough to think that the things that I think are interesting are interesting too, although, that's probably on its way out.

And it's honestly been really helpful for me, because more than anyone else in my life, he models how it's not a big deal. Yeah, there's, sometimes, workarounds that we have to figure out, or I'm like, I know you want to play that game with me, but that game is in nine-point type, and it's such a pain to use a magnifier. Can we just play a more accessible game? And he's like, I get it. Sure. Things like that are just so easy with him that it helps me have a more natural relationship with my own blindness.

PHOEBE JUDGE: You talk about a couple of things, one being, who knows how much vision you'll have, and when your son graduates from high school or another big event, but that even if technology is advanced to such a level where you could be seeing him through some sort of device, that your relationship in that moment might be OK to just be there with him in whatever type of vision that you have and that so much of your relationship is not based on your vision, that you might not need to use the best technology in these most intimate moments of your life.

ANDREW LELAND:

Yeah. Yeah. I really think that's true. I've been thinking about this in the context of all of the AI conversations that are happening. And I recently met with a couple of blind people who work in tech, around the time that the first AI-driven image descriptions were coming out, where a blind person could just hold their phone up to a pond, and then GPT 4.0 is like, it's a pond, and there's ducks floating in it. And that's amazing. And I think, certainly, I would use that when I get to that point of not being able to see the ducks myself.

But there's also, I think, this persistent attitude among blind people, where it's like just like anybody else, you don't necessarily want that digital tool coming between you and the world.

You'll see, if you set up a Google alert for blind innovation or something, you'll just get dozens of laser canes, and blind drinking modules, and just these absurd devices that predominantly sighted people, who have a blind neighbor, who maybe doesn't have blindness training at all and seems incompetent. And they're like, man, this is an example that I heard from the president of the National Federation of the Blind, but I think it's a common one. Like, oh, my neighbor is constantly spilling his drink in his yard, and he's blind. And like, what if I just created a cup that had a lid on it? And it was like, you're basically creating a sippy cup for blind people. What is that?

And these are real examples. Or the laser cane. This cane can detect objects. And it's like, I have a cane that can detect objects, it's called a giant stick.

And I feel it even with Braille. I read a lot of Braille digitally, but then when I got a subscription to a Braille magazine through the National Library Service, which is a free Braille library run by the Library of Congress, I was like, oh, yeah, right. Sitting on my couch with a piece of paper, reading a magazine, that's a different experience.

And I hear people talk about it with accessibility in general. There are cool tools that you can use, but sometimes, just like having your friend, or your partner, or your kid just whisper something in your ear is the better way to do it. And so I think I just wanted to hold on to that possibility that there's not a technological solution for every problem that disability might bring up. And sometimes, it is just that intimacy of being with other people and that directness of connection that doesn't go away either, even with a sensory disability like blindness.

On the flip side of the coin, AI has profound implications for accessibility. And I think there's a lot of reason to be skeptical of it, but also, most blind people I know are really jazzed about the power of multimodal AI to describe any image for them without needing sighted assistance.

PHOEBE JUDGE: Would it be easier if you had lost your vision all at once?

ANDREW LELAND:

I do think about that. I don't know. Part of the problem, but it's not a problem, one of the things that came out of writing this book for me is I just met a bazillion blind people. And so I just have this chorus of voices in my head of things people have said to me.

And I think most of them say two things, which, I think, are both true. One of them is, man, things were easier when I had vision. You don't know how good you have it. Buckle your seat belt. It's pain in the ass. But the other thing they say is, wow, it's actually a relief when I lost my vision, because I could stop obsessing over when I was going to lose my vision, and just lean into that life, and figure out what I need to figure out, and just move on and just be me.

And my book is very, very much about this transitional period that I'm in right now, where I'm like one foot in, one foot out. I'm doing lots of blind stuff, but also still like seeing the ducks in the pond visually.

And a number of blind people wrote to me, and they're like, great book, dude, but wow, it was not fun for me to go back to that time. That was a painful time.

And so I think both things are going to be true. I'm sure that when I'm on the other side of this, whenever that is, and I'm not seeing the ducks, let's just use that as a shorthand, it'll be like, yeah, gosh, I remember when I could just like get off a plane and muddle my way through to the other side of the cab stand without needing any kind of assistance, whatsoever. That was nice. But I also am sure I'm going to be happy to be over the lake, wondering and preparing, and just be like, yeah, OK, these are the tools I need. These are the tools I have. I'm blind. Let's go.

PHOEBE JUDGE: Yeah, the wondering. I wonder, if I were in your situation, if I'd be constantly trying to be doing these tests in my head, thinking, wait a minute, am I now at 5.85%? Has it gone down at what percent? Just always trying to see where I was on the scale.

ANDREW LELAND:

Yeah. I mean, I think that's absolutely a tendency. And it's funny, I've talked to my eye doctor about this. And she's said to me like, I think that there's something about your personality, whether it's you're a writer or whatever, but you are just way more attuned to how much vision you're losing than a lot of other people, which I find hard to believe. But also, I think, some people are just like, yeah, I've got this disease, but I'm just carrying on. And they're not micro-obsessed with it the way that I am. And I think, writing the book, really, it was a great experience, but also supercharged my self-consciousness about it.

But one of the things that I find so powerful about making a daily Braille practice and staying on top of all the blindness skills, tech, and cane skills, and everything is that it takes the pressure off a little bit. Because it's like, if I'm reading Braille, then it doesn't matter if I have 8% or 2%. I'm reading a book. And if I'm good with my computer, and I'm figuring out how to log into Zoom, and join a Zoom meeting, and send 37 emails, and do all of that just with my screen reader, yeah, who cares if it's 6% or 2%?

And so I think, that's probably the reason why I've gone so bonkers, like gym addict obsessive about all of these blindness skills, and staying up on them. And the bulk of my free time is spent obsessing about it, and practicing, and training, and researching is that that's my cure. I am hyperallergic to actual cure stuff, like more power to him. Go for it, guys. Cure RB, and I'll take the pill, but I don't want to think about it. That, to me, is that way, sadness, and anxiety, and depression lies.

For me, the thing that feels really hopeful and exciting is figuring out how to be a blind person who is living a life that I'm happy with. And if that means reading a magazine in Braille on the beach happily, and then being able to send a text message with my phone easily, and then finding my way independently to the snack bar, what else do I want? I'm on the beach. Life is good.

[MUSIC PLAYING]

PHOEBE JUDGE Andrew Leland's book, *The Country of the Blind-- A Memoir at the End of Sight,* was a finalist for the 2024 Pulitzer (AS Prize.

NARRATOR):

This Is Love is created by Lauren Spohrer and me. Nadia Wilson is our senior producer. Katie Bishop is our supervising producer. Our producers are Susannah Roberson, Jackie Sojico, Lilly Clark, Lene Sillesen, and Megan Cunnane. Our show is mixed and engineered by Veronica Simonetti.

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[MUSIC PLAYING]