

Speaker 1:

Welcome to The Eye on the Cure Podcast, the podcast about winning the fight against retinal disease from the Foundation Fighting Blindness.

Ben Shaberman:

Welcome everyone to another episode of The Eye on the Cure Podcast. I am Ben Shaberman, senior director of Scientific Outreach at the Foundation Fighting Blindness. Glad everyone could join us again for another episode of the podcast and today I'm delighted to have Morten Bonde and he is from Copenhagen, which is exciting. Now, Morten is senior art director at Lego Group. He has a wife, two kids, and he also has retinitis pigmentosa. And his journey inspired him to write a book called Sentenced to Blindness: Now What? And the subhead for the book is A Journey from Hopelessness Street to Possibility Road. I know it's on Amazon, because I looked it up, and it's gotten great reviews. And it's also available in audio if I am correct.

Morten Bonde:

Yeah, that's correct.

Ben Shaberman:

Okay. And that's been out about a year thus far?

Morten Bonde:

Yeah, a little less than a year in English and almost two years now in Danish.

Ben Shaberman:

So for our Danish listeners, there's a Danish version. That's exciting. So to just start off the story, I want to get into your book a little more, but obviously, again, you have retinitis pigmentosa and I'm just curious what your journey has been like with that condition. When in your life you started to realize you had vision issues and then when you got diagnosed and really began to deal with the condition.

Morten Bonde:

I was 29. It was in 2002, when after having had a break from playing a game in here in Denmark called badminton. I don't know what it's called or if it even is known in the States, but it is a game almost...

Ben Shaberman:

We have badminton, but it's something we tend to play at picnics.

Morten Bonde:

Yeah, yeah.

Ben Shaberman:

It's not a big game.

Morten Bonde:

Here in Denmark, we actually high in the world when playing in tournaments and I was playing that a lot when I was a kid and I had a break until the age of 29. Almost 10 years I wasn't playing. And I noticed when I was playing with my colleagues that... I don't know what is the name of it. You had the name of the ball, which is not a ball, it's...

Ben Shaberman:

Right. It's called a shuttlecock.

Morten Bonde:

Yeah, that's it. Yeah, the shuttlecock. Yeah. It kind of disappeared in thin air all the time, and it was curious and people were wondering what was going on and I was encouraged to go to an ophthalmologist. And after visiting several ophthalmologists, they couldn't really find what was wrong. So I was sent to Copenhagen, which is the capital of Denmark, and there they noticed, or saw, that I had this first stages of retinitis pigmentosa. And that was in 2002.

So the journey is that I decided... Because I had just started as an art director creative in the advertising industry, and I couldn't really see a really splendid career in front of me if I told people that I was going to lose my sight. So I kind of just lived with it without sharing it with many. So during the course of those years, until approximately 2014, 15, 16, I started experiencing hiccups in daily work because everything was just getting more and more complicated. And I visit the ophthalmologist again, I hadn't been there for almost seven years and it turned out that I was legally blind, which left me with a vision of approximately four degrees. So...

Ben Shaberman:

Wow.

Morten Bonde:

... Looking through a tunnel all the time.

Ben Shaberman:

And you were working as an art director?

Morten Bonde:

Yeah, I [inaudible 00:04:45].

Ben Shaberman:

Obviously vision was an important part of your role.

Morten Bonde:

Yeah, I was approving million dollar commercials that I was leading the production of those. So I was in the film studio, in a dark film studio, with millions of obstacles to navigate through. And for some reason I just did it. I just loved doing it and didn't want to face that I was actually slowly becoming blind.

Ben Shaberman:

Wow. So for the first, I guess, maybe 12 or so years, you just kind of rode it out and didn't really try to address the issue. You just moved forward in your career. But then I guess around 2015, 2016, you had a realization or a transformation you might call it?

Morten Bonde:

Yeah, it sounds so grandiose and so larger than life but it was almost like that because I had been through, I think, since mid-'15 to around the end of '16, I had been on this confusing journey of finding out what can I do? When I'm slowly becoming blind and my identity is really about being a visual art director working for the Lego Group, what am I going to do in my life? So I had this sort of fall in self esteem, self worth, identity crisis, call it what you want, I was around 40. So it makes sense that you around that age start looking back also.

But everything was sort of also impacted by vision loss. And I had this moment when I was sitting in what we call here in Denmark, the job center, which is a place where you get help if you have to find a job or if you need a guidance into a new career or get new training or whatever. And I was sitting there and I had this profound moment where for a moment I felt that it was indifferent if I was alive or not.

It sounds very dramatic, but it was not like I was suicidal or anything, but I was just asking myself, "If I'm not all the things that I think I am, will I be anything?" And at that moment that released all the identities. They were just falling off in one big clash. And I had this epiphany, this voice almost in my head saying, "Morten, what do you want out of life?" And that was just a major moment in beginning to look at myself and figuring out how can I somehow change my perspective on becoming blind? Can I change that around and see it from a different viewpoint?

Ben Shaberman:

Right. It sounds like you basically had to hit rock bottom to really find a way out or up or, I guess, forward is probably the best way to put it. This all happened, it sounds like, in a short period of time. It really happened during this visit to the job center that...

Morten Bonde:

Yeah.

Ben Shaberman:

... You had, as you called it, your epiphany. So what happened after that?

Morten Bonde:

Well, it almost took half a year. I started from there asking myself questions and looking at knowledge that could help me lift myself up from this dark place that I was in, because I was suffering severely from stress and my body was impacted by it and depression. So I was really in a bad place. So I started really looking for knowledge and I started listening to audiobooks massively through almost six month until the summer of '17 where I decided that I wanted to create a new version of myself.

One that can see possibilities in life instead of limitations. And that sounds also very like a headline, but I did make those headlines because that was what I had been doing for my entire career. Coming up with ideas, visualizing scenarios, and then manifested or realize them. And I said, "Why can't I do that in my life? Why can I only do that in my professional career? Why can't I imagine what I want to become like and then try to realize it?"

Ben Shaberman:

So you were listening to these books. Were there certain books in particular that were very inspirational?

Morten Bonde:

Yeah, they were very... I always stumble on that word. Philosophical.

Ben Shaberman:

Philosophical.

Morten Bonde:

Philosophical! Yeah, that's it. Yeah. And there were a couple of books and there were many, but I think one book that in particular made me stop was a book by Viktor Frankl, which he was a psychiatrist experiencing going through the nightmares of being in Auschwitz concentration camp in Second World War. And he noticed that people who had a meaning in life, who had something to look forward to, a goal or a purpose, they survived. While people who didn't have that, they perished fairly quickly in the concentration camps.

And he had this quote where he says, "If you can't change a situation, then you are challenged to change yourself." And that was really, really an eyeopener for me because I could see... I don't compare what he had been going through, but I could see similarities that I can't change the blindness and that's a given. Right now, where we are in science, and medical and all those things and there's nothing that can change right now that I am becoming blind. So I have to live with that.

So do I want that to decide the life that I'm going to live or am I going to decide that? And that was one of the starting points. And also there was a book by Eckhart Tolle which is called The Power of Now, which also was an eye opener into realizing that there is no time other than right now. Everything else is something you in your mind make up or something you try to remember from the past. And you can only live your life right now in this moment. So they were two very important books there.

Ben Shaberman:

Wow, you really got some powerful insights from Viktor Frankl. And the other person is Tolle you said?

Morten Bonde:

Yeah, Eckhart Tolle.

Ben Shaberman:

Tolle.

Morten Bonde:

Tolle.

Ben Shaberman:

Very powerful. So you were subsequently inspired to write your own book?

Morten Bonde:

Yeah.

Ben Shaberman:

And how did that come about what is-

Morten Bonde:

The first idea that I got was that after researching how you can change your mindset, because what I realized was you don't just do that from one day to the other. You can tell yourself, "Now I want to be a person who can see possibilities," but in your life you do what you always do. So how can you change your habits? How can you change all those things that you have taught yourself through a whole life? When you're 40 you know how to do things, you just do them. You are an autopilot, you don't have to think that much. What I read and what I learned was that if you have to change a pattern, you have to do it again and again and again. And here was an opportunity for me to do something that could change the way that I was looking at my obstacles in life.

So I said to myself, "You have to give yourself some tasks, some assignments, that will last almost through half a year in order for you to change your automatic reactions on problems that you encounter in life." So the book became sort of a journal or something that could keep me focused on training myself to see things differently. So I came up with the four challenges, which are mentioned in the third part of the book, who were going to challenge how I was dealing with negativity in my own inner voice, talking me down all the time.

And fear and worry, which was very, very present in my life because I was always concerned about what was going to happen in the future. And then the way that I was dealing with limitations in general and the end, how I train myself to share, tell stories that can inspire people to take back control in their life. I could see that Viktor Frankl's insight into, you have to have a purpose, you have to have a meaningful journey in order to overcome problems in your life. And I said, "Oh, well this is actually meaningful for me to share this whole journey with people who might be in the same situation." And I'm also myself reading the book actually frequently because I tend to forget what I was writing to myself. So that was the idea.

Ben Shaberman:

And it sounds like a book, obviously it might be helpful and meaningful to somebody who's going through vision loss or maybe losing some other ability or grieving something else in their life, but it sounds like it could be helpful to really anybody just to find a better path forward.

Morten Bonde:

Exactly. Exactly. And that's what I experience right now. That people who from all different ages and from all different cultures and careers are actually embracing this book now. And I think the reason why they do that, because I'm touching on something very essential and that is the fact that often, or almost always, it's never the situation that we are in that is the problem. But our thoughts about the situation, our own judgments, about what it is that we experience is what creates the problem.

If you think about it, it's a, "No, no because I'm blind. That's nothing about thinking." Yeah, but you can decide to think about it in a different way. I made a deal with the universe. I said, "The universe, if you're going to take away degrees of my vision, then for every degree of vision you take, I want that back as innovation [inaudible 00:16:49] wisdom." So I give something and I get something and that's a new way of thinking about it. And so I train myself in always shift my own inner dialogue into something that I can

benefit from instead of that it brings me down. And that's where I come back to this very potent lesson that is actually our own thoughts and judgments about the situations that we are in that make them a problem.

Ben Shaberman:

It sounds like you've really found a way to empower yourself to just move forward in a more healthy and positive direction. So I want to talk more about Lego Bricks. So I have to confess, growing up here in the U.S. I was sort of a Hot Wheels and GI Joe's kind of guy. I didn't play with Lego Bricks very much, but I understand they're really popular in Denmark.

Morten Bonde:

Yeah, and I think whole Europe and especially northern Europe, Germany and Scandinavian countries. But today it's everywhere. I think Lego is sort of on the map all around the world. And yeah, I was raised in the home country of the Lego Brick, and that of course was in almost every home when I was a child, everyone had Lego Bricks. And we were playing and building huge worlds and crafts and planes and everything. And so yeah, Lego has been a huge part of my life.

Ben Shaberman:

It's almost using Lego Bricks to create these new things. It's almost like a metaphor for your journey in a way.

Morten Bonde:

Yeah.

Ben Shaberman:

So you have been a fan of Lego Bricks, obviously when you were a kid and further on in your adulthood. How did you get hooked into the company?

Morten Bonde:

Well, I think maybe, when I look back and analyze a little bit upon it, I think back in 2000 and year nine, I probably felt the first signs of burnout probably from being in this industry. And maybe it was actually more an escape from what I was doing rather than seeking opportunities. I think, when I look back at it. There is a chapter about my years in the Lego Group. So I just said, "Okay, I need to do something else." And what I was doing in the advertising industry was very short term deadlines. They were one week and then you had to deliver everything.

And the Lego way of working was more long term. We had longer time to come up with concepts and ideas and it was, in a way, less visual because I was more an inventor of stories than actually sitting in front of the computer and working on visuals. So that was what I did when I started at the Lego Group. And for many years I wrote the scripts for the Lego City commercials, those that were aired on all the Cartoon Networks and all those places and also the mini movies. And so it was more like a story storyteller than a visual craftsman or what you can call it.

Ben Shaberman:

So is there a particular story or project that is memorable for you or you're particularly proud of?

Morten Bonde:

Well, I think there's so many. I think I've done over 40 TV commercials through all those years, so I can't really pinpoint one there. We did sort of a brand commercial for Lego City a couple of years ago, I think it was in '18, which was with some really, really skilled people from Hollywood and that was just amazing. There wasn't extra no level of detail in the CGI, the computer and creative animations. And so that was well really cool to do.

But I think other than that, it has been to be involved in the Lego Braille Bricks project, which is a project started by the Lego Foundation and it literally takes the two by four Brick and transform them into the braille alphabet. When I saw that the first time, I just had goosebumps and my just like, "Wow, that's amazing. I want to be involved in this." So when they launched it, I was the spokesperson for the project and I attended in some early tests in schools in England and that was just a close to my heart project to be involved in and amazing.

Ben Shaberman:

That really sounds like an amazing experience and it's heartening to know that the Lego Group is doing things to accommodate people who don't have vision. How long have you been at Lego Group now?

Morten Bonde:

Wasn't nine, so it's about 11 years. Around 11 years. Yeah.

Ben Shaberman:

Well, congratulations.

Morten Bonde:

Oh, thank you.

Ben Shaberman:

Sounds [inaudible 00:22:46] good relationship. You're thriving and it's interesting to hear about the stories that can be told through Lego Bricks. So my final question is what would you tell other people who might be listening who are on their journey of dealing with an inherited retinal disease like RP, or maybe Stargardt disease, where vision loss is progressive? Maybe they're at an earlier stage or maybe at a later stage. What advice would you give them?

Morten Bonde:

Yeah, I think it sounds fairly easy, but it is really something you have to spend some time in doing. And I think it is to make peace with the condition that you have. So start seeing this condition that you have as sort of a companion throughout life that will teach you many, many valuable lessons. And it come backs to how you choose to look at this condition that you have. And I think the more that you fight it, and you go against it and it make it an enemy, the more difficult life will become. Because you always have that enemy very, very close to you. It's in you. So it is to make peace with it and almost accept it as if you have chosen it yourself.

And I know that sounds much more easier than done, but that's the journey I have been on. And I think that I've more or less accomplished that by getting to know myself much better through mindfulness, meditation and meditation in general, paying attention to what is going on inside my head. What am I

thinking all the time? Is it something that is lifting me up or is it something that's taking me down? And by paying attention to those things... And I have an exercise in the book called Stop Swap Thought, and it is an exercise I did for 30 days where every time I noticed that I had a negative judgment on things, I would say, "Stop. Swap thought." And then I would try to see it from a different perspective. And that kind of started the journey of always evaluating what it is that I am judging out there and then shift the narrative in my head around.

Ben Shaberman:

Well, it sounds like you've reached a pretty impressive level of self-awareness and self-empowerment, so congratulations. And again, I want to remind our listeners that Morten's book is called Sentenced to Blindness: Now What? And it's available on Amazon. There is an audio version, I presume that's Audible, so you can pick that up. And as always, for our listeners, if you have questions about the podcast, you can send them via email to podcast@fightingblindness.org.

Morten, thank you for coming to us all the way from Copenhagen as we record this. It's in the morning here on the East Coast. I know it's later in your day over in Denmark, and I appreciate you making the time to do this podcast with me. It's been really inspirational and enjoyable. And again, congratulations on the book and just all the great work you've done in moving forward in your life. So thanks again, Morten.

Morten Bonde:

Thank you very much for inviting me. I'm really grateful for that.

Ben Shaberman:

Okay. Everyone, please tune in for our next episode and thank you all for joining us.

Speaker 1:

This has been Eye on the Cure. To help us win the fight, please donate at foundationfightingblindness.org.