

Episode 1 - Nicole Kear

Robin Eldridge: You are listening to "The Upside of Down" with Dan Ariely.

Nicole Kear: Things are very surprising to me. I am perpetually surprised by things, which I choose to take as a positive thing.

Dan Ariely: Yeah.

Nicole Kear: Oh, wow! That mailbox was right in front of my face.

Dan Ariely: Where's your gaze now? Are you gazing just in front of your feet?

Nicole Kear: Yeah.

Dan Ariely: Okay, so you don't know what's ahead.

Nicole Kear: Well, theoretically I would scan right I'd start over here all the way on the right and then I'd scan the street and that I'd come back left to right a little higher and then I'd come right to left and now I'm at the level of my eyes and...

Dan Ariely: That feels like a lot of work.

Nicole Kear: It is a lot of work.

Dan Ariely: So if you had your cane out now. Would it be of any use?

Nicole Kear: I don't know. Do you want me to try?

Dan Ariely: Yeah.

Nicole Kear: Look at how awesome this cane is. Really, it just unfurls itself.

Dan Ariely: Yeah, you can throw it in the air and it just almost self-assembles.

Nicole Kear: It does self-assemble, really. It's like a magic trick.

Dan Ariely: Did you notice the guy on our left sitting on the bench?

Nicole Kear: Yeah.

Dan Ariely: And were you conscious of him looking at you or not?

Nicole Kear: Oh, sure I was.

Dan Ariely: Sure, this guy was trying to avoid looking at you in such a clear way.

Nicole Kear: We don't know how to react.

Dan Ariely: Yeah, how do we react and make it feel normal?

Dan Ariely: Hi, my name is Dan Ariely, and in this show, I talk each time with somebody who's sort of like me, in two ways. They've also been through a difficult time in their lives and yet they're also trying to make specific and interesting meaning and contribution with their lives. I was burned many years ago in about 70% of my body and I spent about three years in hospital and now I'm trying to run all kinds of experiments about all kinds of aspects of human behavior trying to figure out what gets us to behave worse and what gets us to behave better. In this show, we will get to have conversations about what we do with all of this. What do we do with our own challenges and injuries? And how do we find meaning? It's about how we make these challenges into better times.

Nicole Kear: Right around here on the streets surrounding this park is where I received my training for my mobility cane. I was very resistant to learning how to use this cane, and my mobility instructor said that I could determine sort of the parameters of my instruction. She was really understanding and said I could choose where I wanted to do the training. So really where I wanted to do the training was the privacy of my house. But because that was a 900 square foot apartment, she thought it might not be...

Dan Ariely: Ideal.

Nicole Kear: Ideal. So...

Dan Ariely: Also, do you, do people, even when they lose a lot of vision, do they need a cane inside the house?

Nicole Kear: No, no.

Dan Ariely: Okay, so it was just both irrelevant and too small, so you needed to go outside.

Nicole Kear: It was irrelevant, useless, right. So I needed to go outside, and she said you can go wherever you want. So I tried to, really I tried to wriggle my way out of it, but when it was apparent that she wouldn't take no for an answer, I thought, where's a private place in New York City that's outdoors? So it was basically the only place I could think of where I could do this essentially, you know, in total isolation.

Dan Ariely: And you picked social isolation and you resisted because?

Nicole Kear: Well, that's a good question, and it's a profound one. I was diagnosed at 19 with retinitis pigmentosa. It's a degenerative retinal disease. What it means is that the photoreceptor cells of my retina are dying. The vision loss that accompanies it is extremely gradual. It's the kind of thing that you can effectively be in denial for a very long time about. The only reason that I noticed it was that I went on a romantic weekend getaway to the

beach with my first ever boyfriend. And I couldn't see the stars at night. It was a very, it's funny, it's a very cinematic way to stumble, but it's exactly what happened.

Dan Ariely: And he said, "Look honey, darling, look at the star, that is such a romantic thing."

Nicole Kear: Right, and I said, "What stars? And he said, "Stop joking around. I mean, they're blazing bright." And I couldn't see them, and so we joked about it. But I just really thought, "That's weird." It really, I didn't have a feeling of dread or foreboding like you would in the movie version, right? It wasn't the telltale cough of the person who's gonna die two scenes later, but I thought, "That is distinctly strange that I can't see this thing that's very bright." So when I went to my ophthalmologist appointment as an afterthought. Really at the end of the appointment, I mentioned to her, you know, this weird thing happened. I couldn't see the stars. And I wonder if it's a problem. And she assured me that it wasn't. But she said, you know, let's be safe rather than sorry. And she dilated my pupils. And then she saw what she called a little something. She was sure it was nothing. And then of course, several specialists later, I had an incurable degenerative retinal eye disease. So I am night blind. I am also color blind with a lot of colors. And I have this extreme tunnel vision. I have about 10 to 15 degrees of field of vision.

Dan Ariely: So when you look straight at something.

Nicole Kear: I can see you for instance. But if I like turn my head...

Dan Ariely: I feel sorry for you. I mean, I look so much better blurry.

(laughing)

Dan Ariely: So you have a narrow field of vision, which means that you more consciously move your eyes around more to understand where you are and what's going on?

Nicole Kear: Yes, theoretically, that's what one should do.

Dan Ariely: You should be.

Nicole Kear: Yeah, it's a whole process. You scan your environment, kind of like a spotlight in methodical right to left strips to sort of make up for the vision that you're not seeing. It slows me down. I have found ways to compensate, but when I need to measure the children's Tylenol, for instance, that's like an ordeal. When I need to adjust the thermostat, that's another ordeal. And that's in the comfortable space of my house. So once I move outside of my house, there's challenges of navigation.

Dan Ariely: So what were some of the realization that kind of were points where you saw something in a kind of a discreet way?

Nicole Kear: Well, the driving was a really big one for me. I lived in New York City when I stopped driving, so it wasn't that I used the car that much, but it felt it had a real symbolic weight to me. And actually I've spoken to a lot of other visually impaired people. It's a big moment for everyone. It's kind of a milestone. They call it surrendering your license.

Dan Ariely: Yeah, you have to give it back?

Nicole Kear: Yeah, I just thought that was so funny that they called it surrendering. I had to go in person to the DMV, wait on this line, and then it was funny because I had really had to sort of give myself a pep talk to do this. I just really did not want to give up my license. Even though I hadn't driven in like five years or more, I just liked having that license. It really did make me feel like things can't be that bad. Look, I still have my driver's license. And the truth was I'd only been able to renew it because I had renewed it by mail and they hadn't given me an eye test. I couldn't have had it if they had. So it was a useless license, but I did not want to give it up. And when I went to give it up, I was very young. I was in my thirties. And so I guess they didn't understand what I meant. He thought I was mistaken. He said, "No, you just have to renew it. It's so easy. Just get the forms. Trust me, it's not that hard. Just take the vision test. You can fill the forms." And I really had to sort of screw my courage to the sticking place and say, "No, I am surrendering. I am trying to surrender for God's sakes. Let me surrender them." So I did. And that was, you know, I felt, when I left the DMV, I remember very distinctly like this tremendous feeling of sadness that also was a tremendous relief. It was a very distinct kind of combination 'cause I felt sort of, I had thrown off a burden of pretending and I had lost something.

Dan Ariely: So, so for a while you didn't tell anybody?

Nicole Kear: At first I only told the people close to me and then what ended up happening is that I didn't tell people. People would meet me. I would make new friendships and relationships and nobody could tell. I had no symptoms at all. And it was a matter of, well, now when do you bring this up? When is it appropriate to bring it up? When is there a natural segue? And there wasn't. And so then time would go on.

Dan Ariely: The first instant of clumsiness.

Nicole Kear: Exactly.

Dan Ariely: Of seeming clumsiness.

Nicole Kear: Right. I mean, looking back, obviously there were segues, but I sort of let them go.

Dan Ariely: Yeah, but it's not part of the normal conversation. Oh, by the way.

Nicole Kear: Right, especially, right. And it's a dark, depressing thing because there's no upside. In the sense that I can't say, "I have this thing, but don't worry, there's an operation," or "I have this thing, but I'm taking medicine." You know, it's still to this day, people ask me about it and they say, "Is there treatment? Is there a cure?" And I have to say, "No." And then they'll say, "So what's gonna happen?" "Well, I'll slowly go blind." And then they're, you know, pained and you're like, "I'm sorry, I know, it's, you know, it's hard." And it's a whole burden, conversation-wise. And at 19, I didn't want that. So I just didn't tell people. And then years would pass. And then I hadn't told them. And then it became this whole other secondary thing of...

Dan Ariely: Of course, how do you say, after you've hidden it from them for so many years?

Nicole Kear: Now it's weird. And then it became decades. Now it's just too weird. So I basically wrote a memoir.

Dan Ariely: To tell your friends. It's like a coming out party.

Nicole Kear: Yes. And in fact, there was a roommate, a very, very close friend and roommate I had lived with who I had no idea. And when he saw my memoir, he said, "It says memoir, but it's fiction, right?" And I said, "No, it's true." And he was flabbergasted. But interestingly, I thought he was gonna be angry. And he wasn't angry. Nobody was angry about it. Everyone...

Dan Ariely: Well, they couldn't. How could they be angry? You're suffering. You're going to go blind at some—

Nicole Kear: I trumped them! You can't be angry. I caught you!

Dan Ariely: So you clearly have a very sunny disposition. Is this something that you always had? Do you always have this? Is it something you're working on?

Nicole Kear: I'm much too lazy to work on anything as hard as having a sunny disposition. To be honest, it's more that I use humor as sort of the only tool in my arsenal of coping strategies. I'm like a real one-trick pony. Humor is very effective for me. It's the only reason I think I'm still standing. Besides that, I don't have much else. And I over rely on it, you know, with the pathology. I mean, there's some times where I really need to stop cracking jokes. So I do just naturally deploy humor to cope.

Dan Ariely: Do you deploy it with everybody or there are particular people that you deploy it more with?

Nicole Kear: No, I think it's with everyone. And it's certainly been useful with my children. To help them with whatever they're going through. We can laugh about things. I always tell them, like, if you can't, you know, you gotta laugh. What else are you gonna do? You know, you gotta laugh or you'll cry. And sometimes you do both. Sometimes I really do start laughing and then end up crying. Because to me, that's what my experience of life is. But no, I don't always have this sunny disposition. I mean, you know, sometimes I'm bleak. But I would have to say I feel things intensely and for brief periods of time. So I mean, I do sometimes feel sad. It's hard. I don't want to stop seeing things. I'm attached to that.

Dan Ariely: It's kind of nice to see.

Nicole Kear: It's nice to see. I mean, you know, honestly, what I think about, what affects me—

Dan Ariely: This is the third time you used the word honestly. I don't know if you know, I study dishonesty.

Nicole Kear: You study dishonesty?

Dan Ariely: I do.

Nicole Kear: Am I a pathologically dishonest person?

Dan Ariely: I don't think so, but I'm paying attention when people say "honestly". It's an interesting thing to say in the middle of a conversation, but up to now you were not honest?

Nicole Kear: 'Cause it does kind of -- It's conspicuous.

Dan Ariely: It's conspicuous.

Nicole Kear: I've been lying up til now. But – Honestly... to be frank... The way that I experience the vision loss mostly is as an inconvenience. Really, it's mostly just an inconvenience. But then, occasionally, I will feel sort of ramifications or the loss of it in a more profound way. But mostly, in your daily life, you're not thinking like, "Oh, blindness." It's not like I'm writing a Milton poem all the time. You know, "Irrevocable night that is falling upon me." It's like, "The thermostat. It just took me two minutes to change the thermostat. But then sometimes you think, "Oh, damn, that's gonna suck. Like, I really would like to be able to see colors." Or really what gets me is, like, my kids.

Dan Ariely: Yeah.

Nicole Kear: You know, I wanna -- I wanna be able to see them, but -- And then I just sort of think, you know, life's not fair and there's worse things.

Dan Ariely: But I think humor is a -- It's a very interesting tool. There's also -- There's a lot of dark humor for all kinds of things, and that humor can almost not be repeated outside of that group.

Nicole Kear: Right. I think you're right. My son had told me something which just made me roll with laughter, And the name of my book is called Now I See You. And he said, "You should write a sequel in like 10, 20 years, and you should call it Now I Don't." I repeated this joke to one of my students recently, and she was horrified. I mean, she was really perturbed. And that was the first time I thought, "Oh, it has a different effect when you're inside of the experience versus for someone who's outside of the experience." But part of the humor's value to me and in my family at least is it aids being open about things.

Dan Ariely: My scars are very visible and I used to not like to walk with shorts because it just exposed how different I am. And it's not the same as a cane, but the moment I have short sleeve or short pants, it's very, very clear how different I am. The cane, I think, also has an understanding of what you have. With the scars, it's very unclear. People can think all kinds of things. For example, in the pool, I always worry whether people think I have some skin condition.

Nicole Kear: Oh, if it's contagious or something?

Dan Ariely: Yeah, that's right. I actually remember the first time I jumped into a lake. A few years after my injury, I was in a summer camp. I was a counselor in a summer camp in Canaan, Maine. And the guy who ran it at the time basically worked on me for a long time. You know, everybody was swimming in the afternoon in the lake. And he tried to convince me for a very long time to take off my long-sleeve shirt. It was summer in Maine. And eventually I agreed and I took my clothes off kind of at the edge of the lake. And I ran as fast as I could on the little dock and jumped into the water to minimize the time that anybody could see me. But it was kind of the first step and after that things became slightly easier. It's still sometimes harder. So it is interesting this signal to ourselves and to others.

Nicole Kear: I am the kind of person that likes to do things in tiny steps. I like to be able to control my kind of exposure. If I'm going to go in a swimming pool, I am not a jump-in-the-pool kind of person. I will get in the pool, but I really have to go in one step at a time. That's just how I work. But there is no way to do that with the cane. There is no way. The truth is, if I use the cane more, it would, I'm sure, be more useful to me. In the sense that I would be able to perceive those nuances that as a person who doesn't use it very much, you know, I don't. I think it's a relationship with the cane. It's really a symbol, too, and it's an identity. I mean, when I take this cane out, everybody knows what that means, and that's most of the utility of it. That's sort of the bind that I'm in, because, yes, it will apprise me to bumps or to curbs or to things like that. But a large part of its value is the fact that it will apprise other people of what I'm dealing with. So the cane is like an enormous big sign that says, you know, "Blind Person". That's what's useful about it. And what's hard about it is the exact same thing. You don't always want to wear a huge sign that says that. I mean, I don't know that people ever want to, you know, sometimes you don't want to wear a huge sign that says anything. You just want to be who you are, which is a person made up of many parts. But when you're wearing a huge sign, that's all people see. I mean, I think it comes down to control, too. I want to control my story. When people see me, I'd like to be able to control if that's the first thing they know about me versus the fifth thing.

Dan Ariely: This is a beautiful dress, by the way.

Nicole Kear: You noticed it.

Dan Ariely: I did.

Nicole Kear: Because I'm not wearing my cane. And, I mean, as I walked here, that's what I wanted people to notice. That's why I wore the dress. But the cane, it feels very kind of emblematic to me. So, you know, I wonder, when did you get to the point where you were, was there a point with--

Dan Ariely: Which I'm comfortable? I'm not.

Nicole Kear: Right. I guess that's the real, you know, real life answer.

Dan Ariely: Yeah, yeah, I'm not.

Nicole Kear: In the movie version, there'd be a big scene where you encountered something and then you conquered it and now you're like totally comfortable and it's not even a concern.

Dan Ariely: Yes. That would not be a good movie, but.

(Laughter)

Dan Ariely: So, the reality was that I did it a couple of times in this camp, and I felt more comfortable around these kids. I think it did relatively little to make me comfortable in other environments.

Nicole Kear: Right. It didn't transfer over.

Dan Ariely: So part of the issue with me, and tell me how it works for you, is this reflection in the eyes of other people. So when I go to a new place, it's very hard for me not to see myself in the eyes of other people. And I see people looking or talking, or if it's kids, of course, they point. And it shifts the focus of attention from whatever I am thinking about doing to wondering and thinking what it is, what other people are thinking. So in my case, I would move from being, if I wore a long sleeve shirt or a short sleeve shirt, I would move from being, 'cause I also have scars on my face and my hands, you could see some anyway. It's not as if I hide everything. So I would move from being less visible to more visible if I took them. But in your case, you would move from being a young woman walking around to a blind person, and also the assumption about what people would think about you with a cane might be worse than your vision implies right now.

Nicole Kear: Oh, for sure. Oh, absolutely. I mean, this is the challenge for me, and I think you're right. I think what's hard about it for me is that it is, it seems very kind of black and white, or from one extreme to the next.

Dan Ariely: Do we want to turn?

Nicole Kear: No, we're going to go straight.

Dan Ariely: Okay. So we did a study once in which we made people feel very uncomfortable in the racial situation. We made up a computer game, which one person saw 20 pictures, and one person saw one picture. And the person who saw 20 pictures had to guess which of the 20 pictures that they had were the one that the other person had. And this was all like yes/no questions. I would say, is the person standing next to a tree, or is the person a man or a woman? And one of the questions you could ask, okay, so now we're getting to a sidewalk, okay, great. So one of the questions you could ask is, is the person white or black? And this is a very good question to ask, because half the people were white and half the people were black. And what we found was that people did not want to ask this question.

Nicole Kear: Oh, interesting.

Dan Ariely: Because it would make them feel a little racist.

Nicole Kear: Right.

Dan Ariely: But sometimes people played with an African American person who actually worked for us. So it made race more salient and they felt a lot of racial tension. And what we also saw was that people were just kind of had a very shifty look. Like they just did not want to look at the other person in the face. They were in a socially awkward situation and didn't know what to do. And I wonder whether when you take the cane, you're increasing social awkwardness.

Nicole Kear: Do you ignore it? Is it more awkward to ignore it? Is it rude to ask about it? You know.

Dan Ariely: Do people compliment about their cane? Oh, you have the graphite model.

Nicole Kear: I guess if people are wondering about it, I would like people to ask about it up front. It's not the only thing that I want to discuss, but I guess to get it over with and out of the way. I guess.

Dan Ariely: You know, on the other hand, it is tiring. When I was growing up in Israel, people were just asking all the time. Israelis are not as bashful.

Nicole Kear: Right.

Dan Ariely: So, and I would get these questions, "So, how do you get injured?" Somebody sits next to me on the bus and asks questions. And then of course they would also recommend treatments and doctors I should go and see and so on. In the US I find that people are probably wondering just as much, but they don't ask and it is tiring.

Nicole Kear: And you prefer that they don't ask?

Dan Ariely: I don't know. It's a really interesting mix. I don't want like just strangers on the street asking, asking, but I think with people that I have conversations, as long as it's kind of an unknown kind of weight in the discussion, it does create a very unpleasant aspect. And you also have to decide how much over simplistic to be, you know, how much is it about giving people the full understanding of what things are versus putting this aside and saying, Let's talk about something else. So in your case, the cane solves the problem to say you're visually impaired, but it does make people think that you're 100% blind. And you could easily just say, "I'm blind," of course, which is not true.

Nicole Kear: Right. Well, I could say, I guess, "I'm visually impaired." Yeah. Because it confuses people when I say, "I'm blind." Even though I am legally blind.

Dan Ariely: Yes.

Nicole Kear: People don't really—

Dan Ariely: The term is confusing.

Nicole Kear: Now that, you know, my kids are older, my daughter handles this quite nicely for me. She's nine. I went to pick her up from camp yesterday. I had to sign her out. And the font was so tiny, I don't know that aunts could see it. I said, "Honey, can you find your name and sign it?" And she said, "Yep, 'cause you're visually impaired."

Dan Ariely: So she said it out loud so people could—

Nicole Kear: Yeah.

Dan Ariely: Could hear.

Nicole Kear: She thinks it's an interesting sort of part of my story. So she likes to tell people, one time we were walking down the street, very close to here, and there was a, she stopped a man with a dog, and he said, "Yeah, my dog's blind actually, "you know, she can't see you." And my daughter said, "That's crazy, so is my mom!" And the man must, he really looked perplexed.

Dan Ariely: Yeah.

Nicole Kear: The biggest blessing of this retinal disease has been a sense of urgency. It's not a constant sense of urgency. I don't think anyone could live that way. But sporadically, I am reminded, "Oh, I'm not gonna see forever." Certainly when I was first diagnosed and I was 19 and I didn't really have many symptoms, That was my takeaway. And it was also a very convenient excuse.

Dan Ariely: Oh, yeah?

Nicole Kear: To do incredibly stupid things.

Dan Ariely: Oh, good.

Nicole Kear: As if a 19-year-old needed such an excuse.

Dan Ariely: Yeah.

Nicole Kear: But I would think, "Ah, better do it now." You know, I really thought of it as an expiration date. I'll still be living, of course, in a very sort of full way, but there's some things, you know, if I'm gonna see stuff, I should see them now. So I do try to-- it gives me that extra push to say yes instead of no.

Dan Ariely: Would you say that the uncertainty helps you or makes you more worried?

Nicole Kear: For me, it's helpful because I think I am genuinely down, very deep, an optimist. What I find really hard about it is the constant nature of the deterioration because you can never kind of get your bearings. I mean, it's actually... You're a parent. It's a lot like parenting in the sense that your kids are going through the terrible twos and they're toddlers and you're just thinking, "What's gonna work? How do I deal with this terrible behavior? How do I manage this?" And then you sort of find a few great strategies and you employ them and just

as you do that, they're in the next phase. And some of it carries over, but a lot of it is all brand new and now they're tweens and "Oh my God, what do you do for this? I just figured out the last thing." And so you're constantly recalibrating. So in a way I guess that's just life, but it is aggravating. I'll sort of make my peace with how things are. And then, oh, I just, you know, now I'm unable to do this thing or I have to find this complicated new strategy to do this thing that I thought I was going to be able to do for a while. And it's frustrating.

(upbeat music)

Nicole Kear: I sort of just assume that one day I won't be able to see. And that's sort of how I plan for things. Eventually at some point, that will happen. And if it doesn't, then I will be pleasantly surprised.

Robin Eldridge: "The Upside of Down" is hosted and executive produced by Dan Ariely. The episodes are produced and edited by DDC International and Newfruit Media, especially Luis Dechtar and Colby Gottert. Sound mixing by Ross Nelson, additional sound mixing, editing, and producing by Daniel Rinaldi. The theme song is "A Okay" by Kayjez. Additional music provided by Musicbed and Marie-Claire Saindon. I'm Robin Eldridge, and I created, produced, and directed the series. If you like what you heard, please pass it on.