

When Glasses Don't Work Anymore - Adele's Story

Your Health Unlocked Podcast E038

0:00:21 - Denise

All right. Well, we have Adele Scheiber on the line with us today, and this is interesting because, as the Executive Director for the National Women's Health Network, I am interviewing the interviewer, so she's on the other side of the bike today. How are you feeling about that, Adele?

0:00:46 - Adele

I have to tell you I have nothing but sympathy for my poor guests because this is nerve-wracking. I don't love the spotlight in this way. I love to kind of direct and, you know, let other people have the spotlight. So, I'm here because I think that this is, you know, important, for low vision awareness month and, you know, whatever I can contribute, I want to.

0:01:08 - Denise

Great. Well, let's just have a conversation about what's happening with you. You know, we do want to make sure that we give proper airing, if you will, to those who have lived experiences, and I have been on the other side of the mic, so I totally feel where you are. But now that you are on the other side of the mic, let's talk about vision loss. What's going on with you?

0:01:33 - Adele

Yes, oh, my God, you're so good at this, Denise. She's my favorite boss, I have to say. I'm going to say that for the record. She's so good at everything I ask of her. [laughter]. So, it's funny. I had perfect vision until I was 25 years old. In fact, I vividly remember filling out the Peace Corps medical stuff and being like, oh, at least I don't need glasses. One more hurdle, I don't have to do, hilarious. And then my last year of Peace Corps, I was traveling home on an airplane, and I looked out the window and it looked like a painting. It looked messed up man, I thought I was dying. Like the lights looked like little shooting stars but they should have just looked like dots and I thought I was like having a stroke. And I go and they're like, oh no, you just have an astigmatism and I'm like a stigma what?? This is super common and at the time I just needed a tiny little prescription for astigmatism and I got my glasses. And you know you'd think that's the end of the story. Right, that's the end of most people's story. And I'm 34 now and it went from oh, I need a slight adjustment once every two years to I need an adjustment every one year. To this last year it got to the point where I couldn't buy, you know, there's these fun sites for all you glasses wearers who like eccentric lenses, like I do, like Zenny and all that. And it got to the point where I would put my prescription in and they're like your prescription is too weird and strong to buy from us, and that became like yeah, that became like the norm.

So, I started getting freaked out because I didn't pay that much attention to the OD and OS.

I was just like, whatever, give me my glasses. Then I did some research, and I was like, oh, I have maybe one of the strongest prescriptions that's possible. Then I started needing one every six months and then I couldn't drive at night. And then my husband, who has been blind as a bat his whole life, was like "you can't see that?" So already I'm blinder than my husband, it's only been nine years and he's you know not had a great time since he was sick.

So, this year it's frustrating, though, because you go in to the eye doctor and they, if they can correct it, just kind of send you on your way.

0:03:56 - Adele

In my experience, there wasn't a root cause examination. I kept being like, "why is this getting so much worse?" Oh, it just doesn't. Some people, it's fine, we can correct it, we can correct it. But, like these last couple of times, they were like wow, this is strong, like it's getting to the point where we can't correct this.

0:04:16 - Denise

Being someone who wears glasses in context but have favored glasses this past year more so than before. You know I get nervous when I go to the eye doctor because I'm always suspecting the worst, and this happens to you every what, eight months?

0:04:34 - Adele

Yeah, it was. For the last two years it's been every six to eight months. I've needed a new prescription and they're there they're applying to you is oh, it just happens.

0:04:38 - Denise

I mean, if that would be a cause for red flags for me that your eyesight was changing so drastically in six months.

0:04:52 - Adele

Right, well, and it's. You know it was a red flag for me and I dealt with it. You know we hear this over and over on the podcast, just kind of brushing me off, and part of it is you know who you go to, which office you go to. Unfortunately, that's true, I've been. I went to three different Empire Vision Works in three different towns these last two years because I just wasn't satisfied. I didn't feel like I was being heard, right.

0:05:15 - Denise

Let's talk about that. Why were you... What was happening? Walk us through that.

0:05:19 - Adele

Yeah, so, first of all, I mean, Empire Vision Works. That's just happens to be what's around me, we don't have, like the best bespoke eye care in this area. It's a small city, right, they're [eye doctors are] not there. You know, they're mid-tier, they're all right, you know, and you have to do your research, right. So, I kind of expected it, but what happens is, first of all, really long wait times, and then sometimes we'll make the appointment. They'll be like we have no record of this appointment. Then you finally do. This was one case, by the way, where I have to say telehealth was not helpful, because now, what they did two times ago was they did my eye exam via telehealth.

0:05:57 - Denise

How do you do that?

0:05:58 - Adele

Badly, very badly.

So what they had, was an assistant doing the things and there was a video and the Doctor was on video and they were...it was like playing telephone and the assistant was actually getting confused because, as we'll learn, my right eye is garbage, it's trash, it's for decoration and she kept being like, "why can't we

get your eye to focus?" And the doctor was like "I don't know, just give her the strongest one. I can't go there to professionally mess around because I'm on a video."

Telehealth has a place, absolutely, but I would say, if you're having a non-routine eye exam, ask when you make the appointment, is there going to be an in-person optometrist there? Because that made all the difference. The second time I went which was, as you know, Denise, recently, it was about two months ago I went and, yeah, because it wasn't being heard, I literally walked in this time and I had to, like, put my baby Karen pants on, and I don't like to do that, I really don't. I literally was like, look, something's wrong and I am not leaving until you do every test that you have or you refer me to a specialist like an **Ophthalmologist** or somebody with a higher degree, because I do not accept that I can't see out of my right eye and that that's normal

0:07:25 - Denise

When you say you can't see out of your right eye, what was your vision like? I mean, just absolutely, walk us through us.

0:07:31 - Adele

Yes, absolutely. So, it's getting to the point. Now I'm wearing these bad boys for these nice cat eye lenses again. Strongest prescription available for astigmatism for my issue with my left eye, old lefty. It's corrected up to about 2040, pretty good. I like to call it the iPhone 3, right, but even with she's laughing at me. But even with my glasses, my right eye, right now I can't read. So, I'm about one and a half to two feet away from the screen and you can see that your health unlocked logo is really big. I can't read it; I just see blur. So, what I see is a bunch of Monet style blurs. If I didn't know who you were, Denise, right now, I couldn't recognize you.

I know you're a person.

I know that you're in a room right.

0:08:19 - Denise

But you can't read. That's it.

0:08:21 - Adele

I can't read, I certainly can't drive if this were my vision in both eyes, I wouldn't legally be allowed to drive, and this is with glasses. So, without glasses, forget it. I can't see hardly any, literally just shapes, just shapes and light out of my right eye. Yeah, it's really scary. It's not fun.

0:08:44 - Denise

So tell us about **keratoconus**.

0:08:48 - Adele

Yeah, so I go in. I'm on high alert and luckily, I get a really good **optometrist**. This time her name is, I think, Amy, shout out to Amy and she spent 55 minutes with me. Now these are usually 15, 20-minute appointments. They'll test you to get you in and get you out. But she listened to me. I was like, they do the one or two, one or two right. And I was like nothing, I don't see anything. Nothing, neither one nor two is working. And she's like, really, cause, we have a camera and this is the problem they took a photo

of the inside of my eye. You know how they dilate your eye or they do the right, and that's usually where they find a lot of the problems, right, the reason I was tricky to diagnose and why keratoconus is tricky to diagnose is because it's not a problem with the inside of your eye. It's a problem with your **cornea** or the **lens** of your eye.

So, they could take a picture and be like well, you don't have cataracts, you don't have **glaucoma**, you don't have a brain tumor, doesn't sound like so, we don't know? Just astigmatism. **Astigmatism** is a vision condition. It's a symptom of keratoconus. It's a symptom of a lot of different things. Astigmatism is when you see auras and it's why I see nothing but shapes and light. Everything blurs together like a kid colored outside the lines, basically. And keratoconus literally stands for cornea cone, really creative guys. And it's a rare degenerative cornea disease where the collagen bonds in your cornea, are on the lens of your eye, deform over time, usually between the ages of 25 and 40, interesting. And slowly your cornea just gets lazy and it's like you know how, like you lean at work, like you slouch, you mean like this all day.

0:10:34 - Denise
Yeah, yeah.

0:10:34 - Adele
Your cornea literally starts to slouch into a cone shape, and what that does is it causes like incredible astigmatism. And I mean imagine if, like fog, fog, fog, fog, fog, fog right. Like layers of fog or layers of clear nail polish over your eye right, because there's too much tissue that you can't see through right.

And it's missed a lot because it's very hard to see with the naked eye, unless it's really bad, which we'll talk about that. The stages of keratoconus. And there's only one test that can officially diagnose you, for it called the corneal topography, and most eye doctors don't have that test in the office yeah, yeah, yeah.

And because it's rare, it's one of those things, it's not on the decision tree until somebody pushes. You know what I mean. So that's what it is and that's what I have. And this woman, you know this optometrist. She sat with me, she listened to my symptoms and she was able to informally diagnose it by essentially checking with a light the surface of my eye.

0:11:38 - Denise
Incredible.

0:11:40 - Adele
She was so cool. She literally, it's so bad in my right eye that she's starting to be able to see it with the naked eye. I also have it in my left eye old lefty, the good one, but it's so slight right now that you that I wouldn't. If I hadn't been diagnosed, it wouldn't have been caught and I could have lost more vision in my left eye, which is scary.
So she saved my vision.

0:12:01 - Adele
I credit her for saving my vision Incredible.

0:12:03 - Denise
You know keratoconus is. I looked it up in the dictionary and it's not there.

0:12:09 - Adele

Yeah, no, nobody knows what it is. I know, yeah, yeah, I had no idea. She scared the bejesus out of me when she said it. I was expecting, like you know, oh, you have something. But she found a thing and I was like a what? And then she starts talking about the treatment, and that scared the bejesus out of me.

0:12:25 - Denise

Let's talk about the treatment. Yeah, because you, I mean you have this diagnosis that cannot be found in the dictionary, so you're trying to understand what it is and how do you go about fixing it? As we all do. Once we find out we are sick, what do we do to fix it? So, walk us through that. What was that like?

0:12:46 - Adele

So initially terrifying, but actually I feel very lucky now. I had two days, I would say a two-day pity party when I got my diagnosis, where all I did was cry and eat McDonald's. But then I thought about it, and I really researched it. Essentially there are two. You can't cure it. That's the unfortunate part. There's no curing, there's no "oh, we'll just do LASIK, and we'll fix it." And in fact, LASIK can make it really bad and a lot of people get misdiagnosed with something else when they have keratoconus and then LASIK ruins their eyes.

So, I'm really lucky that I was diagnosed properly. But essentially, the first line of treatment is something called **crosslinking**, which sounds really... basically a paper was written on it, seminal paper in 2013. The FDA approved in 2016 and what they do, is they try to strengthen the collagen bonds by, it's an outpatient procedure, they inject your **cornea** with **riboflavin**, which is essentially vitamin B. They numb you first. I hear you're going to have to take a Xanax either way. That's terrifying to me.

0:13:53 - Denise

That's a whole different podcast. We call that **white coat syndrome** because I have that when I go to every doctor. I don't care if I'm going to get you know something very simple done. I have white coat syndrome. I get it.

0:14:05 - Adele

I really do. I avoided it for a while until I was like I want to live past 60, let's just keep going with the doctor. But they inject it with vitamin B, and then they hold your eye open, Clockwork Orange Style, and literally it's what they do. They put UV light in your eye for about 30 minutes to an hour and what that does, I'm one of the only people on earth where staring into the sun is actually helpful because for some reason it's been indicated that that will strengthen the collagen bonds of your cornea. That combination of vitamin B and the UV exposure and what that does is it stabilizes the Keratoconus where it is. So, my vision right now is really bad in my right eye, but if I get this done, which I'm supposed to be getting done in February, it should freeze it.

0:14:56 - Denise

Right, it should freeze it, well okay. So, that being said, is there an oral treatment? IE supplement, IE vitamin B. Is there something someone can begin to take if they suspect? You know and then confirmed, obviously, with your doctor, but is there something that people can really add to their regimen, maybe that they take vitamins?

0:15:19 - Adele

So that's a great question and unfortunately the answer is no because that was my first question. I was like, okay, collagen, do I just need to take collagen? Right? And apparently it doesn't work that way. But there is something you can do to try to prevent this. Now, to a certain extent, this is genetic. Some people are more prone than others to it. But the number one thing you can do to protect your eyes from care to conus **is to not rub your eyes**. Rubbing your eyes is actually really dangerous. I didn't know this until October. So, like when you sneeze and you just do that, or if you sleep on your stomach and you're, that's actually really bad if you have unstable collagen bonds, if you have delicate bonds, because that can actually like rip them. Who knew right? And there's actually a really strong correlation between people with seasonal allergies aka myself for my whole life and people who develop Keratoconus that's bad enough. They need these treatments because they're always rubbing their eyes. So, if you want to protect your vision, don't rub your eyes. Get eye drops! Who knew?

0:16:25 - Denise

Well, let's talk about some of the harder aspects of being diagnosed and treatment. And you know, at the Network here we always talk about removing barriers to care. Did you experience any barriers to care?

0:16:39 - Adele

Yeah, and I have great insurance. I have great insurance, I'm health educated, I have a car, but I mean truly, getting an appointment with a qualified optometrist was very difficult. Appointments are really backed up. I was actually talking to Amy, and she was like "the problem is there aren't enough of us and, more importantly, there's not enough equipment" and so the wait times and the backups are because, you know, only one person can use these highly technical machines at a time, plus a lot of people. They'll have good general insurance, but they won't have eye insurance. I almost opted out because glasses, I can afford those. So, yeah, there's a manpower issue, there's an equipment issue and there's an insurance coverage issue. I mean, you get all you run the gamut there, and that's to say nothing of transportation and environmental factors. I can't imagine. I tell my husband all the time I'm like "what would somebody who couldn't afford this do?"

Because there's also a chance even though I'm literally almost blind in my right eye that my insurance won't cover this.

0:17:46 - Adele

I will tell you. This is what the optometrist told me when I went in for my official consult, they want to see progression, right. So, they want to see, okay, so a corneal topography, right. So how big is the cone? How big is the cone? How bad is the deformity? A normal eye, the cone is 30 tiny units. A really bad Keratoconus is 90, so three times higher of a cone. I'm at 47, which is bad. Not great. It's not 90, but it's pretty bad. Essentially, they want you to wait. Insurance wants you to wait to see you, no matter where you are, you get from like a 47 to 49. They want to see it get worse. But the problem is, if it's caught late, the damage is already done. Right, yeah, I'm at a 47. I can't fricking see at 47. Do you know what I mean? So, there's a chance they'll go back and be like well, because it's stable now, which it's not, I think they will cover it, but like well, you haven't progressed much more. So, we're not going to cover this and I'm going to have to pay out of pocket and the surgery is about \$4,000. That's a possibility, it's very real and I'm very lucky that I can do that. But I literally joined a support group online for this and there I saw a med student, a **medical student** talking about this and he was like "I have it. I can't afford the surgery. I don't know what to do. Can I just wait on this? What will happen if I wait two years because I just can't afford this?" And this is a guy. He's going to serve people. I

was so pissed off for him. Like he was going to serve people, he was going to be a doctor and he can't afford the surgery to save his eyes, you know so yeah lots of barriers. Nobody knows what this is. There is no ribbon for Keratoconus.

0:19:29 - Denise

Well, okay, so you have a wonderful attitude in dealing with this.

0:19:35 - Adele

Well, there's reason for that, which is they can correct my vision, so there's some good news here.

0:19:40 - Denise

So, there is good news, for what would you recommend for someone who is recently or newly diagnosed with this, and they may not be so optimistic?

0:19:49 - Adele

Yeah, I would say, do go read the Wikipedia article about it. It's very well written and it gives a lot of really good primary sources. And I know that when I was told what this was, right, she was throwing scare. I mean, this is true. She was trying to explain to me all the treatments right, first cross-linking. If that doesn't work, you might need a corneal transplant, that's terrifying, right, like I asked, am I going to go blind from this? And she said, "not necessarily," which is not the answer. That's not confidence Building right.

But you got to remember this is an optometrist who does not specialize in this. She diagnosed it. She's a smart cookie, right. But there are people and then luckily, I'm with one now I'm with a group, now this is all they do is cornea disease, right, and when you start so that I would say, ask for a referral, she was very good. So, ask for a referral from somebody who just does cornea disease and don't listen to anyone else until you find that person who can adequately look at your case and whatever, because at least you know that you're just getting anecdotal evidence and you're just getting what people? Until you talk to a specialist you're really not going to, or people who are dealing with the disease.

That's the second thing. The Wikipedia article was written by corneal specialists on that. And the second thing I'll say is I was at an all-time low, and then I went on Facebook and there is a Keratoconus support group on Facebook. It has, I think it's for the whole country. I think it has like 2000 people in it. But I got to tell you I learned so much about the kinds of prognosis I could expect the vision I could expect. It was extremely supportive, I would say. And then I even looked on TikTok. I searched Keratoconus on TikTok, and I immediately saw a bunch of like fun and lighthearted videos about the different ways to put the contacts in and out and like it's okay. It was just very comforting to find that community and that really is what brought me out of it and helped empower me to ask the right questions when I did get the surgical console.

0:21:58 - Denise

Community is key in your healing process and your journey. Yeah, and that is very clear. Anything else you want to let our listeners know.

0:22:06 - Adele

Yeah, I just want to say if you're diagnosed with this, it's pretty rare unless you really let it go that you're going to have to deal with a transplant. So don't get scared. The other thing is, the good news about this disease, and a lot of corneal diseases, is if you get the right treatment cross-linking be the first line, and then scleral contact lenses or RGB lens, basically, contacts are the only thing that can help. The bad

news is, glasses aren't going to help you anymore. The good news is, if you get the right contacts, you can be up back to 20/20 vision, and that's what I'm looking forward to. That's what motivates me. Why is that? It's so funny.

Diagnosing this stuff really hard to do, but actually fixing it is literally just a matter of getting something that presses your eye right. It just presses down [laughs]. It just pushes the cone down in a way that's not dangerous to your eye. That's what I'm waiting for. That's what all these months of building up to getting those lenses. So, this is I like to say this could have been a brain tumor, this could have been glaucoma. This could have been one of those non-curable eye diseases. So, I try, whenever I get bad news, to focus on the things that are good and, at the end of the day, even if this is only going to be about a year of my life where I'm figuring this out, getting the surgery, fixing [it], and I'm lucky. So just focus on, I would say, focus on what you can be grateful for in that situation, because now I laugh about it. I used to, you remember, you remember, I used to squint really hard at the screens.

0:23:34 - Denise

We just thought you were always angry at the work you know.

0:23:39 - Adele

No, I literally, like everybody, would make it so big and I'd be sitting there like what the heck does that say? You know, now I don't have to do that, so that's nice, because they got me my, these are my last stop glasses. They corrected me as much as they could. But yeah, find community, be grateful and do be a Karen. Like, it's okay, you need to ask. If you leave and in your gut you know something is wrong, then you didn't get what you needed out of that appointment right and, quite honestly, I knew something was wrong two years ago and I waited two years to really force the issue and if I hadn't, maybe I would have gotten surgery sooner and I wouldn't have to deal with the blindness right or the low vision.

0:24:20 - Denise

Who is to say. But you know, advocating for oneself is something that I know that the National Women's Health Network is really looking forward to helping women do better.

0:24:29 - Adele

Yes, yes, this was the third thing I decided to do. I called you, I called my friend Amy, who asked me to get a second opinion, and then I was like I got to get on the podcast.

0:24:38 - Denise

Yes, Well, you, look from the National Women's Health Network's perspective. We need you and we need to have your eyes healthy because you do a lot for us in the communications and marketing department and leading that. So, we appreciate you and want you to be healthy and look forward to you having restored your eyesight.

0:25:02 - Adele

Thank you and I just want to say on the record the National Women's Health Network, but particularly you, Denise, have been incredible about this, you know, with medical appointments, with making sure that I had the time and the space to get what I need. So, thank you for that and thank you for interviewing me today!

0:25:17 - Denise

It was fun. We should do this at least every other month.

0:25:19 - Adele

I agree, I agree, you're a great interviewer [laughter], all right, all right.

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