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"What Can You See?"

The Full-Length Description of My Vision

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So, what does it mean to be legally blind, anyway? I suppose the technical, or "legal," answer would be something like, "visual acuity that measures 20/200 or worse at best possible correction." But this is such a vague answer that includes so many vastly different kinds of visual impairments. The truth is, vision is unique for every individual; so, if you take ten people who are all legally blind, there is a very good chance that no two have visual abilities that are remotely similar to one another.

Throughout my life, one of the questions I am most asked is, "So, what do you see, exactly? Can you describe your vision?"

This is a very fair question, but one that is not so easily answered. You see, vision is relative. How can I begin to tell you what I see when I have no clue what it is that you see? In much the same way that a child who's never tasted chocolate cannot miss it, I can't begin to compare my sight to that which I have never known. And for sure I cannot tell you what I don't see – how could I?

Let's try by starting with the easy things. What does it mean to have 20/20 vision? We've all heard those numbers and know that they're

good, but what does it mean? Simply put, it means that what most people can see from a distance of 20 feet, you can also see it from 20 feet. So, the law says we are blind if we must stand 20 feet away from a sign to read it when most others can read the same sign from a distance of 200 feet. This is 20/200. But remember, this is with "best correction." If glasses can fix your vision, then by definition, you are not legally blind.

Now that we have the easy part cleared up, everything gets a lot more complicated. As I've noted, this term casts a very large net. So, how do I see? Something I have learned is that the trusty old eye chart with the big "E" on top is really nothing more than a ball-park figure. Which line you are able to read tells the doctor where to start when he is flipping those lenses, asking, "Is it better now? How about now? Now?"

But when that giant letter "E" is the only letter you can read, or maybe you technically can't read it but you know it's an "E" because that's what it was the last 100 times, then the paradigm breaks down. You might have heard someone say they have 20/25 vision or 20/30 vision, but I bet you have never heard someone say they have 20/147 vision. No, it seems the next stop after 20/100 is 20/200 and then 20/400; because once you hit this category, you're in the, "Gosh, I really don't know" level of acuity. This is where I am.

To be fair, it's impossible for a doctor to tell me a measurement like that when I know that my ability to read a sign depends on how I tilt my head, how bright the room is, how tired I am, and a number of other factors. Likewise, my brain's ability to anticipate what a sign should say for sure plays an enormous role in whether or not I can "read" it. (Like the letter "E," or the word "STOP" on a red street sign.)

My right eye is entirely blind. It didn't used to be; actually, for the first 19 years of my life, it was my dominant eye. But I was born with severe myopia, which is the fancy word for "near-sighted," and that means that the shape of my eyes was wrong. If a perfect eye is a perfect sphere, mine would have been smooshed too flat. Because of this, my retinas had to stretch over a much larger surface area than they ought, and they had stretched quite thin, making them very fragile. Trouble.

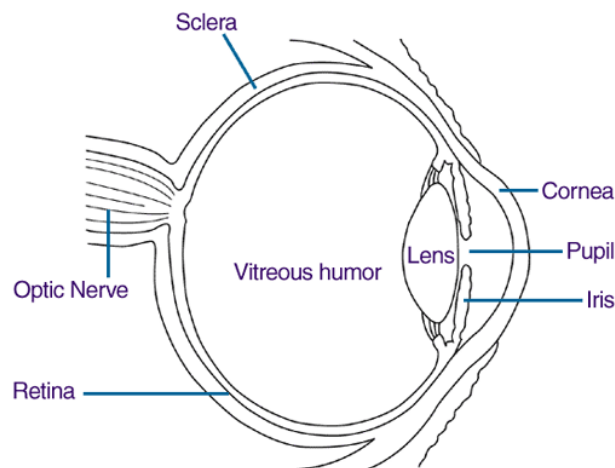


Image from nei.nih.gov.

When we are growing children, there are a lot of things our body needs to help us develop properly that, once we are fully grown, we have no use of anymore. In our eyes, we have a gel called the vitreous which does just that. We only need this until we are about 8 years old. After that, it just sits there in our eyes doing nothing until we are middle-aged or so, at which point it will shrink away and disappear. Most people don't even notice this except for a few odd

flashes of light they might notice in their 50s or 60s.

But for a few of us, this seemingly innocent eye goo is anything but benign. For me, the vitreous decided to shrink away a bit early. In my left eye, this happened at age 16, and in my right eye at age 18. Both times, the gel failed to make a clean separation from my thin retinas. Imagine trying to peel the shell away from an undercooked, still hot egg. Needless to say, my retinas tore, causing hemorrhaging and the need for several emergency surgeries.

Why several? Eyes are fragile and finicky. Imagine that same egg that you've now destroyed while trying to remove the shell – how successful would you be at putting it back together perfectly, membrane and all? And that's just an egg! The first thing they do in this operation is remove that problem-causing vitreous, then they delicately patch up the retina, and finally they put a belt around my whole eye, called a scleral buckle. But eyes are very delicate and the retina is at risk of tearing again, and for me, it did so several times in both eyes.

In my case, they also removed the lenses in my eyes, as I had juvenile cataracts, which were likely to worsen after all the operations. My right eye never regained any vision in the end, but my left eye did. While I am eternally grateful that my left eye has sight (or I would be completely blind!) it was a very difficult adjustment for me. Losing sight in one eye requires much getting used to and this caused me much anxiety until I did. But that was not the only transition I had to make.

The removal of my lenses means that I now require reading glasses. Very thick reading glasses. As a child my near-sightedness meant that there was no distance too close for me. When I really wanted to see something, I would take off my glasses and put the item, say, a book, right up to my nose to read. In my new state, this is no longer possible. I can't read things far away, and I can't read them up close either. My new reading glasses (+8.5) are nearly as thick as my old distance glasses (-14).

Alas, we are only just starting to graze the iceberg in describing my vision. You see, a lot of funny things happen to the muscles and nerves of eyes that can't see. I was born cross-eyed, and though I had surgery as an infant to fix the muscles so that my eyes would work together as they ought, losing the sight of just one eye undid these efforts. When you don't use an eye, the muscles atrophy, kind of like if you were to stop using your legs and then found you couldn't walk. When your eye muscles atrophy, they turn inward. But I suppose that while this is bothersome, it has no impact on my vision since I don't use that eye anymore anyway.

But there is one thing about my eyes that you'd notice before any of the others if you were to meet me, and that is the problem of nystagmus. It is kind of unbelievable how much brain wiring happens in the first six months of life. Your vision is the first thing to get all wired up, and if information is not being sent, then the brain will use that unused space for some other function. I was born with very low vision, and since my brain couldn't make much of the world around me, the wiring got confused—that's the easy way of saying it. Nystagmus is an uncontrollable shaking of the optic nerve

So, how does that affect my vision? I didn't used to think it did, since it doesn't generally seem to me that the world is shaking. But I've thought about this much, and I have come to realize that my brain merely compensates so as to not make me motion sick all the time. If I look at black and white stripes, or maybe blinds on a window, I will get extremely dizzy since the lines do in fact move up and down in waves.

Luckily, the world has very few stripes in it naturally. The other way to compensate is to find a position to hold my head that causes the least amount of shaking. They call this the null point, and it means that I nearly always hold my head to one side or the other, or tipped backwards. I suppose that is a characteristic sign of someone with low vision. I don't do it consciously, and in fact, I have to be quite conscious to not do it. But on days when I am very tired, the shaking is much worse and sometimes a null point cannot be reached. If your eyes won't sit still, it is very difficult to focus on something long enough to comprehend what you see.

So, what can I see? The best comparison I can think of would be that of gazing at an impressionistic painting with your right eye closed. Tilt your head a bit, to get the painting centered. You get the overall gist of what is happening in the scene, but details are left to the imagination. It's easy to guess what the images are, since if you are looking at a landscape, you can anticipate that brown and green objects would be trees while pink and yellow might be flowers.

This is why routines and standards make life a lot easier for people with low vision. Going to a new place with unusual décor is rather like impressionism meeting surrealism. Combine Monet with Dali, and you'll probably stand there for an eternity trying to understand what on earth you are looking at!

So, what do I see? The best answer I can think of is, "It's complicated."

You Don't Miss What You Never Had

What It's Like With Tunnel Vision

Tauru Chaw



Christi with Mt. Foraker in Alaska in the background.



What I see. (Photos from "About Us" on our website.)

Stretch your hands out in front of you and make a circle with your thumbs and index fingers. The area inside the circle is what I *can* see. There may be faint snippets of my hands, but not much more. It's not that the area outside of the circle is dark or black, as is usually depicted to illustrate how people with retinitis pigmentosa see; it just doesn't exist. Only what's inside. But what is inside is clear and good. Normal, you'd say.

It never occurred to me while growing up that I had tunnel vision. I thought my vision was normal. Now looking back, it makes sense

why I always bumped into things. I understand now why cluttered spaces make me cringe.

Imagine how a gecko sees. It probably has almost 360 degrees of peripheral view. So to a gecko, a normal person's 180-degree field of view is, well, "limited." The gecko would even consider this to be tunnel vision. But a 180-degree field of view is good, right? It's normal. It would seem strange to be able to see what's behind you while looking straight ahead. But to a gecko, you're missing a huge range. But to you, you're not "missing" what you can't imagine having.

In many ways, I can't imagine having a wider field of view. To be able to see 180 degrees is incomprehensible to me. Can a person looking straight ahead actually see to his or her sides?

I know now that it's possible, and that it's normal. It is as if you were to wake up one day and realize that you should be able to see 360 degrees around you like a gecko. It's unfathomable, isn't it? You would no longer have to turn your head to see what's going on behind you. But that's how a gecko sees: almost 360 degrees; and that's how a person with normal vision sees: almost 180 degrees. I see however many degrees the circle my hands make in front of me represents. And this is "normal" for me. I'm not "missing" what I never had.

I always knew there was something unusual about my night vision, or the lack thereof. This, not my tunnel vision, which I didn't know about at the time, was what I told my optometrist about when I was 30 years-old. He dilated my eyes and probed deeper into my retinas.

After a while, he sat back with a heavy sigh. I knew something was wrong. He had a strong suspicion that I had retinitis pigmentosa and so he referred me to a retina specialist. Tests soon confirmed his suspicions. The news, though devastating, shed "light" on the issue. It explained my inability to see at night, and it made me realize I had tunnel vision, which explained why I often didn't see things.

I remember being with a friend at a beach some time ago. An airplane trailing a banner flew over us. My friend pointed to the airplane

and read out the banner. I tried to find it, but I couldn't. I heard it, but I never found it. My eyes couldn't scan the sky fast enough to find the roaring engine of the plane. Imagine using the hand-circle analogy above to scan the sky for an airplane. And imagine the frustration of hearing it and knowing that it's up there somewhere, though never finding it.

Retinitis pigmentosa is hereditary and it's degenerative. A defective gene causes the cones and rods in my retinas to deteriorate over time. Ultimately, the area that I see closes in and it may eventually disappear altogether. The degree of deterioration varies from person to person. I'm 40 now and consider myself lucky with the vision I still have; however, my 40's will most likely see a faster deterioration of my retinas than the previous decades. Only time can tell what will happen after that, but it's a sure thing. As of today, there is no cure to stop this degenerative process or to reverse it.

So, what is it like to "see through my eyes?" Imagine seeing the world through empty toilet paper rolls. You can still see with clarity what's in view, but things are "missing." For example, if you're looking at your mom's face, you may not notice the bike at her side, or the car next to her, or the dog sleeping on her neighbor's porch.

You will most likely start scanning in order to see what's all around you. The bike will then appear, so too will the car and the dog. And other details will show up, too. So scanning will become second nature to you.

My eyes have been like this since birth. I don't even think of scanning – it just happens naturally. Though I may not see something right away, eventually it may appear. Sometimes I do miss things altogether. It's especially apparent when I drop something on the ground; it can take a long time to find it because I have to scan the entire area. Nowadays, when I drop a coin, I don't even try to look for it. Perhaps out of knowing that it would take too long to find it, or out of the embarrassment of looking for something that's obviously right there in front of me. But the psychological impacts of my vis-

ual impairment are another story. Most of us with a disability will have a story or two about this, and each will be unique and intimate.

As for night time, imagine putting on sunglasses and walking into a bar while still looking through the rolls. This is when I notice my blindness the most. Not only do chairs, tables, and people disappear, but also space. You can still kind of see, but it's dark, really dark, and the absence of peripheral vision makes things disappear. This is why I bump into things.

Yes, it is unfortunate that such conditions exist; however, I am fortunate to still be able to see what I can see. Others with retinitis pigmentosa may only see through pin-holes and consider my field of view wide. And there are people with other forms of visual impairment who may not see at all. So I am fortunate.

When Christi and I thought about riding a tandem bike across America in 2009, we wanted to see if we could really do something like that. Just the two of us. No sighted-person to guide us or help us. We wanted to see if two legally blind people could actually navigate their way across the country. Our combined visions helped then, and we are hoping that the same teamwork will steer us across the Americas in 2012 and 2013.

What I like most about our endeavor is that we are entirely independent of any sighted person's assistance or presence. The journey will truly be a testament of the abilities of the visually disabled. The blind leading the blind ...16,000 miles across two continents.

(Check out "About Us" on our website for a visualization of how my eyes scan.)

Tauru Chaw and Christiana Bruchok are **Two Blind to Ride**, a legally blind couple who plan to ride a tandem bike across the full length of the Americas starting January 2012. Join their adventures and help raise awareness about blindness and the abilities of the blind.