



The Patient Perspective on Living with Glaucoma

If the clinical research industry wants to run more patient-friendly glaucoma trials and develop therapies that patients will be excited about, it's vital to take the patient perspective into consideration.

When I was 33 years old, I learned I was experiencing progressive damage to my optic nerves, one of the hallmarks of glaucoma. My name is Richie Kahn and I'm a #glaucomaniac.

The first thing I did after confirming my diagnosis was talk with my wife. The second thing I did was put on my patient advocacy hat. Over the following eighteen months, I learned as much as I could about my condition, spoke with other patients facing a wide variety of circumstances, and never hesitated to ask questions. But I found myself on a path I hadn't expected to travel when I learned that, despite all clinical signs of my disease appearing stable, my vision had continued to deteriorate. In the span of those eighteen months, I lost 15%-20% of my vision and I hadn't even noticed.

Needless to say, I've learned a lot along the way as it relates to glaucoma basics, diagnosis, treatment pathways, and the importance of advocating for yourself.

A QUICK PRIMER

Before we dive into potential treatment pathways and the patient perspective, a quick primer on glaucoma itself. Believe it or not, glaucoma comprises a multitude of conditions that lead to damage to the optic nerve, the nerve that connects the eye to the brain. This damage is typically caused by increased pressure in the front of the eye due to fluid build-up which, if not treated, can lead to irreversible vision loss. Glaucoma is a chronic condition; it stays with you for life. When properly treated, vision loss caused by glaucoma can often be prevented or slowed. But even when receiving the appropriate course of treatment, for about 10% of patients that vision loss continues to progress.

DIAGNOSIS AND TREATMENT

Before we dive into potential treatment pathways and the patient perspective, a quick primer on glaucoma. In order to accurately diagnose glaucoma, your ophthalmologist will evaluate a handful of factors. The Glaucoma Research Foundation's *Understanding and Living with Glaucoma* provides a helpful breakdown regarding diagnosis and treatment options which I've expanded on below:

- **Tonometry:** Drops are used to numb the eye before a tonometer is used to measure eye pressure. The average range is 12-22 mm Hg. It is possible to develop glaucoma when your pressures fall within this range, as was the case with me.
- **Perimetry:** This is where your visual field is mapped. You're given a cursor or clicker as though you're playing a video game and asked to stare straight ahead. When a spot of light appears, click the cursor.
- **Pachymetry:** Simply put, this is when a safe, painless probe is used to measure the thickness of your cornea. A cornea that is thicker than average may indicate pressure that is also higher than average. Likewise, a thinner cornea may indicate low pressure. To get a clearer understanding however, a pressure check would need to be performed.
- **Ophthalmoscopy:** Here, your eye is evaluated using a special lens. The doctor will look at the shape and color of the optic nerves and carefully review for damage. Eye drops will be used to dilate your pupils to make this process easier. You'll be extra sensitive to the sun post-



dilation, so you'll likely want to use sunglasses on the way home from the doctor's office.

- **Gonioscopy:** This is when a special lens is used to visualize the angle between the iris and cornea.

If a diagnosis of glaucoma is made based on the results of the above tests and exams, your doctor will work to create a treatment plan that is right for you. Before beginning treatment, a second opinion is highly recommended.

Lowering your IOP

When treating glaucoma, the name of the game is to lower your intraocular pressure or IOP, the pressure generated by the fluid build-up inside your eye. Eye drops, laser surgery, incisional surgery, or a combination of these tools may be utilized to attempt to achieve this result.

Eye drops:

Many doctors and patients rely on eye drops to either decrease fluid production or improve drainage, thereby reducing pressure in the eye. It is important to use these drops correctly and take them according to your daily schedule. Often, drops can be used to maintain healthy eye pressure for quite some time. But I know from my personal experience that these drops aren't fun or easy to use. The bottles in which they are packaged make it challenging to apply the proper dose. Once applied, many patients report that drops sting, burn, or cause redness and inflammation. As a result, the American Academy of Ophthalmology indicates that 50%+ of glaucoma patients don't stick to their prescribed treatment plans.

Laser surgery:

If you have concerns about medication adherence or your ability to use drops correctly, you may want to discuss laser surgery with your doctor. Selective Laser Trabeculoplasty or SLT is frequently used in place of or in addition to pressure-lowering drops as a first course of treatment for glaucoma. Having had the procedure performed in both eyes, I can tell you it is both relatively painless and, well, a little strange. When asked to describe the experience to someone who had never had the procedure, I



believe I said something about being shot in the eye but with low intensity lasers. Not painful or particularly uncomfortable. Just oddly specific.

When you head to the doctor for SLT, you'll first have an eye exam. Next, pictures will be taken before drops are used to numb your eyes and a lens is inserted to prevent you from blinking. Your doctor will then use a low energy laser on the drainage tissues of the eye. This process takes only a few minutes. While I was able to feel the laser, I categorized it as a minor annoyance and not something that would prevent me from repeating the procedure if needed. Furthermore, when used as first line therapy, SLT can lower your IOP by 30% which is as good as most gold standard eye drops, and the benefits typically last 3-5 years.

Incisional Surgery:

If drops or SLT fail, your doctor may suggest incisional surgery such as Minimally Invasive

Glaucoma Surgery (MIGS). MIGS procedures are tailored to patients with earlier disease. They require smaller incisions, thereby reducing the risk of complications. While they are safer than many surgeries, they are often not as effective.

MIGS procedures often involve microsurgical instruments and/or tiny devices that work a few different ways. Some procedures remove fluid from the eye, others improve fluid outflow, some are performed in tandem with cataract surgery, and others are performed independently. Here's a short overview of a few common varieties of MIGS procedures:

- Trabecular surgery: The eyes drainage canals or trabecular meshwork are manipulated or bypassed without causing damage to other mechanisms in the drainage pathways
- Miniaturized trabeculectomy: Tiny tubes are put into the eye to assist with fluid drainage
- Internal shunts: Tiny tubes and openings are used to improve drainage

THE PATIENT PERSPECTIVE

One of the fascinating things about vision loss is that, like me, you might not notice it. In fact, your brain is so good at processing information that it fills in the blanks for you or, at least, fills them in as best as it can. When my wife and I are out for a walk and I start grinning like an idiot, it's usually because I think I see a fantastic neighborhood dog. And maybe I have, previously, in that exact location. But unfortunately, what I often think is a dog is in reality just a rock or mailbox.

But whether a dog, a rock, or a mailbox, it's critical to find a way to cope that works for you. For me, humor helps.

As does staying positive. If my vision continues to deteriorate, I'll be able to process sound faster and plow through audio books. If I'm no longer able to run outside without assistance, I can partner with a running guide or a seeing-eye dog. Running is another way that I deal with my diagnosis, and while I won't blather on about the benefits of exercise, I will say that running helps keep me sane.

And if I can't find the dog poop in the backyard? Well, I'll have a built-in excuse for why my wife has to do it for me.

Besides having a good attitude, I also find immense value in action. For me, that means working with researchers to incorporate the patient perspective, connecting with patients, and volunteering my time and unique skill set. Working with researchers provides a sense of purpose and empowerment. When I'm lucky enough to connect with other patients, I can serve as a sounding board and sometimes alleviate a bit of the stress and fear they're experiencing. When I share my story, I can build awareness

of the importance of getting your vision checked and maybe even save someone else from symptom-free vision loss. After all, they don't call glaucoma the Silent Thief of Sight for nothing.

These are just a few examples of the ways I manage my diagnosis. In addition to developing adequate coping mechanisms, it's also critically important to build your emotional support network. Whether that comes from a team of individuals you surround yourself with to actively participate in your care, friends you vent to when the going gets tough, or loved ones you confide in about your hopes and fears, the important part is understanding you're not alone. Across the globe, there are over 76 million individuals living with glaucoma and that doesn't take into consideration all the friends, family, and supporters that have their back.



The Importance of Advocating for Yourself

My vision loss has continued to progress, something I initially discovered because I was constantly talking about my diagnosis and working to build awareness of the importance of screening for vision loss. One of these conversations led me to a wonderful doctor who invited me to visit him at his clinic for a... seventh opinion? I jumped at the opportunity and learned about my rapid and unanticipated vision loss.

I wasn't satisfied with all the question marks surrounding my disease, so I kept pushing. Advocating for myself. Looking for answers. I was evaluated by a neuro-ophthalmologist, a doctor

that specializes in the intersection of the brain and the eyes. I had MRIs taken to make sure I didn't have a tumor and to confirm that I hadn't had a series of mini strokes, both possible explanations for the damage to my optic nerves. I even went through a battery of genetic tests that took several months to come back but ultimately provided some answers. As with so many things in life, glaucoma isn't necessarily cut and dry. Thanks to the barrage of tests, I learned that the damage to my optic nerves is a result of a pathogenic change to the Wolfram gene and a related protein encoding abnormality. While this doesn't impact the course of treatment, it does mean my disease progression is less predictable than most cases.

If it weren't for that seventh opinion or those genetic tests, I wouldn't understand my disease as I do today. In fact, there's an excellent chance that I wouldn't have visited the glaucoma clinic for another few months during which my vision loss would have continued, and all without my knowing.

Wrapping It All Up

As luck would have it, my visit to the glaucoma clinic came just as I was putting the finishing touches on this whitepaper. A few things stood out to me:

- When you visit the doctor, expect things to take a little longer than usual. Thanks to COVID-19, there are new processes and procedures in place that may make it take longer than usual to get you through your appointment. Everyone is trying their best to keep patients and employees safe. Take a deep breath, say thank you, and give yourself plenty of time.
- You need to make it a point to become familiar with the ins and outs of your patient visit, i.e. what to expect, which tests should be performed, etc. If something seems amiss, be sure to voice your concerns.
- Last but certainly not least, don't be afraid to ask questions. If your concerns aren't being addressed by your care team, be ready to politely and assertively push back. The goal is to leave your appointment feeling confident, empowered, and ready to play an active role in your care.

Whether your glaucoma is newly diagnosed or something you've dealt with for years, the best way to improve the likelihood of achieving your treatment objectives is to become 1) well-versed in the nuances of your disease; and 2) an active participant in your care. By sharing my story, hopefully I can help you do just that.



References:

Glaucoma Research Foundation. (2020, October 14).

Understanding and Living with Glaucoma.

https://www.glaucoma.org/GRF_Understanding_Glaucoma_EN.pdf