

Sunday Review | OP-ED COLUMNIST

# Am I Going Blind?

Frank Bruni FEB. 23, 2018

They say that death comes like a thief in the night. Lesser vandals have the same M.O. The affliction that stole my vision, or at least a big chunk of it, did so as I slept. I went to bed seeing the world one way. I woke up seeing it another.

This was about four months ago, though it feels like an eternity. So much has happened since. I don't mean all the tests and procedures: the vials upon vials of blood; the mapping of major arteries in my neck; the imaging of tiny vessels in my brain; the first injection of an experimental treatment (or, maybe, a placebo) into my right, dominant eye, where the damage occurred; then the second injection; and then, last week, the third.

I mean the rest of it. I went to bed believing that I was more or less in control — that the unfinished business, unrealized dreams and other disappointments in my life were essentially failures of industry and imagination, and could probably be redeemed with a fierce enough effort. I woke up to the realization of how ludicrous that was.

So I flailed on two fronts. I tried to grow accustomed, day by disorienting day, to reading and typing with a thick, dappled fog across the right half of my field of vision, which was sometimes tilted and off-kilter. I felt drunk without being drunk, dizzy but not exactly dizzy.

I also fought not to be angry and afraid, a struggle familiar to anyone with a significant illness or disability. The fear arose less from what I'd already lost than from what I might lose still. Over the next five years, there's a roughly 20 percent chance that what happened to my right eye could also happen to my left. I could go blind.

The odds are on my side. But the stakes are enormous. So how am I supposed to process this? Where on the spectrum of optimism to resignation — of hope to dread — do I position myself?

On that first morning, several hours passed before I accepted that something was seriously wrong. I figured that I was just groggier than usual. Maybe I needed more coffee.

As I sat at my computer transcribing a long interview that I'd just done, I repeatedly took off my eyeglasses to clean them, convinced that the smudginess of my vision was some streakiness on the lenses. When I finally gave up on that, I rinsed my eyes with water — to no avail. It was as if someone had deposited a blob of petroleum jelly in my right eye and nothing would dislodge it.

The next morning I visited my ophthalmologist, who for many years had kept tabs on my run-of-the-mill astigmatism and fine-tuned my prescription so that I saw 20-20 with each eye. He said that in this case I needed a *neuro*-ophthalmologist. (I didn't know that such a specialty existed.) I found one, Golnaz Moazami, who could squeeze me in a few days later, and after three tedious hours of staring at or into charts and colored patterns and sophisticated machines, she told me this, in a rat-tat-tat fashion:

I had almost certainly experienced what is colloquially called “a stroke of the eye,” whereby the optic nerve is ravaged by a brief reduction of blood flow and thus oxygen. The name for this condition is nonarteritic anterior ischemic optic neuropathy (N.A.I.O.N.), and it afflicts perhaps one in 10,000 Americans. But I'd need extensive blood work and tests to rule out other possibilities.

This tends to occur after the age of 50. (I'm 53.) It typically strikes during sleep, when blood pressure drops, and is sometimes associated with sleep apnea, diabetes, hypertension or the use of pills for erectile dysfunction — none of which applied to me. I was a mystery.

I would be surprised, Dr. Moazami said, by my brain's eventual adjustment. It would edit my right eye out of the equation so that my left eye could guide me on its own, leaving me with entirely serviceable vision. There was even a possibility that I'd get some vision back.

But there was a much better possibility that I wouldn't. There was nothing I could do — no diet, no exercise, zilch — to influence the outcome. Worse, the “stroke” revealed anatomical vulnerabilities that meant that my left eye was potentially in jeopardy, too, and there was no proven script for protecting it.

Certainly I should drink plenty of water, especially before bed, because dehydration causes or aggravates blood-pressure dips. Probably I should take a baby aspirin daily, to promote blood flow. Possibly I should avoid high altitudes, where oxygen is thin. Mostly I should pray.

I'm not good at religion. I'm better at drama. I called Tom, my partner of more than nine years: “Would you still love me with a cane and a bad habit of bumping into things?” I called three of my best friends: “I'm fat, I'm old and now I'm a Cyclops. Do you think there'd be interest in the movie rights?” I called my sister: “You have to give me your dog. But first you have to retrain him as a companion for the blind.” My phone soon ran out of juice. My body was pumped full of it.

An estimated one million Americans are legally blind, meaning that their corrected vision is no better than 20/200. A few million more have life-altering vision impairment. Just a tiny minority of both groups were born that way. The rest lost their sight after seeing perfectly well. They almost always got some warning, followed by a period of waiting and dread.

Macular degeneration. Glaucoma. Diabetic retinopathy. These are more common culprits than N.A.I.O.N., whose obscurity helps to explain the lack of progress in treating it. There's no huge market of potential patients for drug companies to profit from. No deep pool of test subjects to study.

Dr. Moazami confirmed that I had N.A.I.O.N. a week after our first visit. On some people, its impact is subtle; they lose only peripheral vision. But the central vision in my right eye was compromised, in an unsubtle fashion. When I use that eye alone, I see the cloudy contours of things, and the nearer an object is, the thicker the clouds are. I can tell that a paragraph is here. But I can't make out a single word.

“This is bad, isn’t it?” I asked Dr. Moazami.

“This is bad,” she answered, then added, after an awkward pause: “I’m sorry. I have nothing to offer you.” But wait, there *was* one thing: a clinical trial of an experimental treatment, and she could tell me how to get into it — if I wanted to go that route. I did. So I soon added a new, time-consuming dimension to my already busy life. I became an ophthalmological guinea pig.

Ever looked at pictures of an optic nerve? I’ve appraised a Louvre’s worth of them. And I can’t get over how fragile it seems, this slender thread, fed by about a dozen minuscule blood vessels, that tethers the back of the eye to the brain and alone decides whether you get to see the setting of the sun or the rising of a soufflé.

“I consider optic nerve damage the holy grail of solving blindness,” Neil Miller, a professor of ophthalmology, neurology and neurosurgery at Johns Hopkins University’s medical school, told me. “If you have somebody who’s virtually completely blind from cataracts, we can cure that. Corneal damage? We can cure those patients. We can help a lot of patients with retinal disease. But there is really very little that we can do to restore vision that’s damaged from optic nerve disease.”

Rudrani Banik, one of the neuro-ophthalmologists who monitor me during the clinical trial, told me to think of the nerve and its surrounding sheath as “a cable within a pipe.” My pipe, she explained, is a quarter of the normal size, so if the nerve swells — as nerves do when bereft of oxygen — it’s more likely to press up against the pipe and be hurt. “Everything is congested,” she said. “Anatomically, we call it a disc at risk. I hate to use that term because it scares patients.”

For the first month after my diagnosis, I’d catch myself absent-mindedly rubbing my eyes, as everyone does, and terror would sizzle through me. Had I been too rough? Was my congested nerve still O.K.? During a run through the park, a gust of wind blew dirt into my left eye, and I panicked: I couldn’t allow any injury to it. I no longer had a spare.

Nights were worst. If the left eye were going to quit on me, it would probably do so then. I quaffed two, three, four glasses of water just before my head hit the pillow. Superstitiously, I also took my baby aspirin then. If I somehow forgot to do either, I bolted out of bed, no matter how close I was to sleep, and made amends.

Then, in the middle of the night, when my bladder screamed, I hesitated before

opening my eyes. What if I'd had another "stroke"? It was the same every morning: a stab of suspense, then a gale-force sigh of relief. I could still see.

And I *can* still see. The oddity of my situation — the emotional riddle — is the distance between the manageability of my current circumstances and what tomorrow could bring. For the moment my handicaps are minor. I read a bit more slowly than I did and frequently get a pinched, deadened sensation behind my eyes. My typos have multiplied. My texting is a joke.

But extra determination and care compensate for most of that, and I've learned that the best response to weakness is strength: Prove to yourself what you can still accomplish. I had a column due three days after I woke up to my newly blurred vision. I wrote it on time — and kept to my usual pace from then on.

I cut bait on just one of four speeches scheduled for the subsequent months. I devoured more books, not fewer, partly on the theory that I should take advantage of my vision while I had it, but also to train and reassure myself.

On a visit to Washington, D.C., I had a drink with a friend who works for David Tatel, a distinguished federal appeals court judge there. I filled him in on my odyssey and assured him that I was O.K., except for my anxiety about the future — about my independence, my competence. I'm a writer, for heaven's sake. Explain how I do that without sight.

"If this hits my left eye," I said to my friend, "it's game over."

"Why?" he asked, then told me that Judge Tatel was blind.

Tatel, 75, welcomed me into his chambers a few weeks later.

He was given a diagnosis of retinitis pigmentosa when he was 15 and informed that he would someday lose his sight. He coped by not dwelling on that. He went to college and law school. He married and started a family. Then, around the age of 31, his vision began a sharp decline that would end in blindness six years later.

He and his wife, Edie, had two of their four children after that point. He adapted to his disability; his workplace adapted to him. Various digital advances — in particular, text-to-speech technology — helped hugely. "I'm really looking forward to self-driving cars," he laughed, emphasizing that innovation is transforming the lives of people without vision.

Of course he has regrets. In a speech last year for the Foundation Fighting Blindness, he noted that while family members have become “true audible artists,” describing everything that they pass on nature walks, “I still can’t see the clouds and flowers and potholes myself — or my wife’s beautiful white hair.” He believes that he knows what his grandchildren look like, from the sounds of their voices and his memories of their parents, but he can’t be sure. “Have I created it?” he wondered.

That same afternoon I met Peter Wallsten, 45, the senior politics editor for The Washington Post. When he was in his early 20s, he learned that he had Stargardt disease, a juvenile form of macular degeneration that eroded his vision over the ensuing decade. He works on an enormous screen that shows letters in a gigantic font, and he listens to writers’ stories and does some of his editing by dictation.

“This is the important thing to remember: It’s not your brain that’s affected,” he told me. “It’s your eyesight.”

He added, “There are things much harder than this.”

Harder than this: A friend of mine was recovering from a stroke before the age of 60. Another friend was grieving the death of a 39-year-old spouse. A mother in her mid-40s was questioning whether a rare cancer that she had battled for years was really and truly defeated.

I found myself taking inventory of the obstacles and upsets that people I knew were dealing with. There were children with autism. Parents with Alzheimer’s. Financial crises. Career disasters. Addiction. Abuse.

And that was merely the stuff at the tip of my nose, in plain sight. How much else lurked beneath the surface? Show me someone with a seemingly unbroken stride and unfettered path. More often than not, he or she is hampered and haunted in ways that you can’t imagine.

And despite my eye disorder, I’m in clover: economic security; access to good health care; a durable relationship with a man whose face will delight me for as long as I’m able to gaze at it, after which his voice, which I also adore, will do. What I’m going through is what everyone endures as the years accumulate and the wear and tear starts to show. It’s aging writ vivid and large. I’m bumping up against my limits. The trick is figuring out when to focus on them and when to look away.

I increased my disability insurance. I deleted Machu Picchu, with its high altitude, from my bucket list. I carved out the necessary hours and showed up for every eye appointment. The third injection was my last, and there's no meaningful sign that the treatment is salvaging my devastated nerve, as it's meant to. But it's too soon to reach any conclusions. I'll be under observation for eight more months.

And I'll try to put N.A.I.O.N. out of mind, apart from the water and aspirin. Joseph Lovett, 72, a filmmaker whose 2010 documentary, "Going Blind," chronicles the slow worsening of his vision from glaucoma, told me that his best counsel was that "you cannot spend your life preparing for future losses." It disrespects the blessings of the here and now. Besides, everyone lives in a state of uncertainty. Mine just has funky initials and fancy medical jargon attached to it.

I'm no longer fit for summits, but I crested a modest hilltop on a run a few weeks ago. I wasn't after the view, but there it was, the Hudson River, gray and wavy and magnificent. I could see upstream. I could see downstream. Lucky, happy me: I could see for miles and miles.

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