



The Country of the Blind

A Memoir at the End of Sight

Andrew Leland

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of the
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For Lily and Oscar

What so clearly appears as an end is better understood as a beginning whose innermost meaning we cannot yet grasp. Our present is emphatically, and not merely logically, the suspense between a no-longer and a not-yet.

Hannah Arendt, *Men in Dark Times*

The splinter in your eye is the best magnifying glass.

Theodor Adorno, *Minima Moralia:
Reflections from Damaged Life*

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Author's Note

I've changed the names of a handful of nonpublic figures to protect their privacy.

Introduction: The End Begins

I'm going blind as I write this. It feels less dramatic than it sounds. The words aren't disappearing as I type. I'm sitting comfortably in the sunroom. The sun is rising like it's supposed to. I can plainly see Lily sitting next to me, reading in her striped pajamas. The visible world is disappearing, but it's not in a hurry. It feels at once catastrophic and commonplace—like reading an article about civilization's imminent collapse from the climate crisis, then setting the article down and going for a pleasant bike ride through a mild spring morning.

There's no cure for retinitis pigmentosa (RP), the condition I was diagnosed with more than twenty years ago, so I usually see my eye specialist every other year. At these visits, I go through a full day of tests, but these just track the decline. At the end of the day, we have a short conversation about the someday promise of stem cell or gene therapy. During my last visit, she showed me an illustration of how much vision I had left. It reminded me of ice cubes melting in hot water: two small, wobbly ovals in the center, and two skinny shapes floating along the sides. The wobbly ovals represented the central vision I still had, and the strips were my peripheral vision. I had about 6 percent of what a fully sighted person sees. My doctor frowned graciously as she gestured at the skinny french fry shapes. "When those go," she said in her medical deadpan, neither cheerful nor grim, "your mobility will become more limited. Those two strips of residual peripheral vision are what you're using to get around."

Describing what I can't see is surprisingly difficult, mostly because my brain adapts to it so quickly. I have severe tunnel vision, but what I see doesn't look like a tunnel; the walls of the enclosure aren't visible. I have the

strongest sense of the contours of my blindness in periods when my vision changes—when suddenly there are things I don't see that I ought to, that I saw until recently. I bump into furniture in my house that hasn't moved in years. I'll put a cup down for a moment and it disappears. I'll painstakingly rake the wobbly ovals and slender french fries of my residual vision across the table's surface again and again, and when I finally find the cup, it's standing blamelessly in what even a few weeks ago I would have described as "plain sight." It's still in plain sight—it's just that my sight is growing less and less plain.

RP is painless, if you don't count the bruises that accumulate from violent encounters with inanimate objects, like chairs that haven't been pushed in all the way or cabinet doors that have been left to hang open. The most painful part so far has been the not-knowing. I live much of my life these days in a speculative mode, like a science-fiction writer who looks at the present and tries to imagine the future. As I cook dinner, or walk my son, Oscar, home from school, or find my way from the airport to a train station in an unfamiliar city, I ask myself: What will this be like when I can't see? I perceive everything with this paradoxical double vision: through sighted eyes, and through blind ones. While most futures are difficult to see, shrouded as they are beneath the fog of contingency, mine is doubly difficult to visualize. The crystal ball remains clouded over.

But I can't just accept blindness as a visual death sentence. The blinder I get, the more curiosity I feel about the world of blindness and what possibilities might exist there. So I went out in search of that world, to find a more accurate image of what might be waiting for me.

• • •

Blindness is a radically distinct way of being in the world. Humans are so fundamentally visual in their understanding and experience that blindness requires its own domain. The early science-fiction writer H. G. Wells's short story "The Country of the Blind" takes this idea literally, imagining a civilization of blind men and women who live without any knowledge or

need of the sighted world, in a hidden mountain valley. One day an explorer called Nunez, separated from his expedition in a rockslide, ends up falling into this forgotten valley. There he discovers the fabled country of the blind, which has existed without sight for fifteen generations. Every person he meets was born blind, just like their parents and grandparents and great-grandparents before them. They don't even understand the concept of sight; their language has no word for *see*. As he comes to terms with his situation, Nunez proceeds with supreme confidence, repeating the old proverb to himself like a mantra: "In the Country of the Blind, the One-Eyed Man is King."

I find myself approaching blindness a bit like Nunez, as an accidental, curious, and sometimes wary visitor to this strange and often beautiful country. For now, I still feel like an outsider. My partial sight sets me at a remove from those who can't access all the visual information that I do; I'll never be native to blindness, the way that those born blind are. My brain developed visually, and learning blind skills, from reading with my fingers and ears to drawing mental maps of my city, requires a radical shift in the way I relate to the world around me. But unlike Wells's character, who escapes in the end, I'm here to stay, slowly becoming a naturalized citizen.

There's a common set of questions a blind person is almost guaranteed to hear if they spend enough time in public, at least in the US. Strangers will turn to them on buses or sidewalks, and ask, *How do you eat? Who dresses you? Can you sign your own checks?* Questions like these, which suggest that the world of blindness is an infant's world, where a blind person can't even put on a shirt or bring a fork to his mouth without sighted assistance, are infuriating. They exacerbate the painful difference that the experience of disability carries—no one else is being asked how she accomplishes the most basic tasks of daily living as she waits in line for her breakfast burrito. But for someone like me, who still feels like a tourist in the country of the blind, wondering when I might actually move here, these questions have some urgency: I need to know how I will live, and what kind of blind person I'll be. How will I travel independently? How will I write, and read, and work?

How will I watch movies, or appreciate art? How will I experience my son's journey from little kid to teenager as a blind father?

This book isn't merely the account of my own experience of vision loss, though; it's the chronicle of an intentional journey I took into the greater world of blindness. Writing it has pulled me deeper into blindness than I otherwise would have gone at this stage in my retinal degeneration. As I lose more and more vision, I feel a new motivation to temper my speculations and fears with knowledge and direct experience. Over the last few years, I traveled around the country, exploring every place I could think of where blindness intersects with contemporary life.

Blind people don't benefit from the sort of large, well-established institutions that Deaf communities have built. Part of this may be because hearing blind people don't face the same barriers to verbal communication that Deaf people do, and so they never needed to develop a distinct shared language. Language is the most important feature in the formation of a community, and sign language is no exception. In the US, the signing community is as linguistically and culturally rich as any other language community. Many Deaf students describe their arrival at schools like Gallaudet, the world's first fully Deaf-centric university in Washington, DC, as a revelation. Having spent their childhoods feeling isolated from hearing families and peers, suddenly they're plunged into a world of Deaf culture and language, where they no longer need accommodations to eavesdrop on a conversation or attend a lecture.

Still, I found pockets of concentrated blind life. In Florida, I attended the national convention of the largest blindness organization in the US, wandering among thousands of blind people in the halls of a colossal Orlando convention center, a forest of canes tapping and colliding, and for the first time I felt the power of being in a space where the blind outnumbered the sighted. I met blind activists from across the political spectrum who made annual visits to their representatives in Congress, and others who marched in street demonstrations with their white canes in one hand and placards in the other. In California and New York, I met blind geniuses working at the cutting edge of digital accessibility who spend their days soldering circuit

boards, designing 3D-printed objects, and editing TV soundtracks. I found myself drawn to these media-obsessed tinkerers, who seemed to approach their blindness as a feature that spurred creativity and invention.

I met people who said that their blindness meant nothing to them—that it was a mere attribute, like hair color—and others whose blindness utterly defined and upended their lives. Some recoiled from any mention of the medical cause of their blindness, let alone the prospect of a cure, while others cultivated personal relationships with research ophthalmologists, demonstrating an impressive fluency in the argot of cellular and molecular therapeutics. I sympathized with all of these positions, even as I wondered which attitudes I would adopt for my own life. I tried to understand how blindness was changing my identity as a reader and a writer, as a husband and a father, as a citizen and an otherwise privileged white guy.

In the middle of the COVID-19 pandemic, I took a trip to Colorado, where I spent two weeks at a radical blindness training center. I wore vision-occluding sleep shades for eight hours a day, five days a week, relearning how to use a gas range and chef's knives, and how to cross busy Denver intersections, all from a team of blind instructors. It was only a simulation of blindness, but one that helped me understand how I might respond, and who I might become, when the ice cubes of my residual vision finally melt away.

Figuring out what sort of blind person I should be has become in some ways indistinguishable from the ongoing process of figuring out what kind of person I am, or want to be, regardless of my disability. As I breeze past forty, it seems obvious that one never fully escapes the painful, exhilarating process of self-exploration and reinvention that begins in adolescence.

The more I explore the world of blindness, the more I come to think of it as a domain that extends well beyond the realm of disability. The late critic Greg Tate wrote:

Race, generally equated with politics, is really in the American context a branch of metaphysics, aesthetics, and anthropology representing a far broader body of concerns where you can readily leapfrog between sex, death, religion, criminality, linguistics, music, genetics, athletics, fashion, medicine, you name it, in the name of African liberation and self-determination.

Is blindness, then, another branch of American metaphysics, with its own concerns one can leapfrog between? Sex, death, and religion, to be sure, alongside medicine, technology, assimilation, cinema, art, literature, mythology, politics, and on and on. Following Tate's formulation, these concerns also point toward liberation and self-determination: all of blindness's intersections and interventions into the wider world come with an awareness of the marginalization that blind people experience in their contact with sighted society, whether in the form of overt oppression (blind people denied employment or educational opportunities solely on the basis of their disability) or more insidious and subtle diminishment (the everyday experiences of blind people made to feel incompetent or miraculous as they go about accomplishing the basic tasks of living).

I feel an immense sense of connection to this world, alongside a persistent feeling of discomfort and alienation. This is part of the experience of becoming disabled—entering a club that millions unwillingly join every year. But it's also a basic feature of contemporary life: you may not like your family, but that's another club you can't leave. Even more voluntary identities, like one's religion, hobbies, career, or tastes, can have this character of clubs one both values and disdains. Susan Orlean, describing the bitterly competitive, insular world of orchid collecting in her 1998 book *The Orchid Thief*, wrote that it, too, was like a family: "It was some kind of way to scratch out a balance between being an individual and being a part of something bigger than yourself, even though each side of the equation put the other in jeopardy." Blindness is becoming all of these things to me: a bickering, annoying family and a loving, supportive one; an interesting hobby, whose fellow hobbyists can inspire and delight as well as irritate and depress me; an identity that I embrace and revile, that defines me and has nothing to do with who I really am. Orlean identifies this contradiction as fundamentally American: "the illogical but optimistic notion that you can create a union of individuals in which every man is king." In this way, I have a uniquely American experience of going blind.

The progression of retinitis pigmentosa—gradual, narrowing tunnel vision that usually ends in blindness, at an unknown date—is a powerful engine of

ambiguity. I have become intimately familiar with the pain of living in between: not quite blind and not quite sighted. I called a guy with RP who'd lost his usable vision decades ago for computer advice, and after telling me I was a "lucky bastard" to still have the central vision I did at my age, and that he'd "kill" to be able to see the screen of his TV or laptop, he added sincerely that he thought his life was easier now than it was when he was in the thick of losing his vision. "I don't have to wake up and worry about what's going to happen with my eyes today," he said. "I know they won't work, and I can get on with my life." The RP Facebook page refreshes itself every day with accounts of people afraid to unfurl their collapsible canes in public for fear of being called out as frauds, the challenges of their own partial blindness (spilling drinks, asking for rides) overshadowed by the looming threat of "real" blindness, qualified by their constant assurances that they "still drive" or "still work" or "still get around OK" with the shrinking central vision they're so lucky to have, but God help them if it ever gets to the point at which they can no longer rely on their eyes.

Visiting that page is among my guiltiest pleasures. Reading the endless scroll of self-pitying posts, buffered by the cheerleading replies they generate ("you got this"; "RP strong"), I feel another kind of alienation: it feels less like a blindness community and more like a community of disease-sufferers, praying for cures and living in fear of the inevitable blindness to come. But as easy as it is to judge these fellow travelers, I engage—in my own way, and usually not on Facebook—in the exact same cycle of self-pity, fear, and football-coach-style encouragement (*cloudy eyes, full heart, can't lose*).

We all live with this sort of ambiguity: beginning in 2021, many people I know celebrated the end of the COVID-19 pandemic again and again, each time thwarted by a new variant, a new spike in deaths, until we finally had to accept that the virus was never going away, and that a more complicated, confusing, and infinitely less comforting endemic reality would persist. So much of life, and loss, exists in this space between binaries: a divorce that doesn't end a relationship; a move that brings too much baggage to the new destination; a dying relative who's no longer alive in the way we remember him, even as he breathes the same air we do for years. As painful as the

extreme might be in these situations—severing the relationship, forgetting your homeland, mourning your dead—finality also offers relief that ambiguity denies us. Living in this weird shadowy landscape between blindness and sight has forced me to reckon with this, and to try to let go of my desperate desire for resolution.

My inclination is to just put my head down and barrel into blindness, becoming proficient in all of the skills it requires and then moving on with my life. But the reality of RP makes it hard to turn entirely away from sight. I feel as stymied by the vision I still have as I do by the vision I've lost.

When I was in Colorado, wearing sleep shades and learning how to navigate with a white cane, I had to enter unfamiliar environments and orient myself within them. I'd listen to the echoes the metal tip of my cane made as it hit different surfaces—that's carpet, that's tile, this sounds like it must be the metal fire door. Any engagement with the unfamiliar is like this—by degrees, we feel our way through a situation that can at first seem strange and unwelcoming. But with enough persistence, and a spirit of discovery, solid and defined contours gradually emerge. The space becomes familiar, and eventually it feels like a room you've lived in for months or years. This is what writing about blindness has done for me. It's no longer a legendary, proverbial sci-fi country, and has instead become a real place, populated by real people. My hope is that this book will encourage the sighted reader to likewise discover the largely invisible terrain of blindness, as well as other ways of living and thinking they might not have previously considered.

There are a few common souvenirs that sighted tourists tend to take away from day trips to the country of the blind. The primary one is pity masquerading as empathy: "How difficult their lives are," one might conclude, while more quietly affirming, *Thank god for my eyesight*. There's also the satisfaction of a voyeuristic curiosity: How do they eat, or find their way home from the store, or really know how attractive their partner is? But a longer stay raises more philosophical questions. How does anyone know the world? Does vision deserve the privileged place it holds at the top of the hierarchy of the senses? How much of perception happens in the eyes, and

how much takes place in the mind, regardless of which senses supply its stimulus?

The questions I'm still hounded by arise from the conflict I see between the value of disability—the beauty and power I've found in blindness—and its almost definitional sense of loss and exclusion. How can a thing that causes so much alienation also be a source of growth and joy? How can something that estranges us from so much of the world also bring us closer to it? Activists sometimes frame their disability in terms that echo those used by other marginalized groups—locating pride in their oppressed identity. But does blind pride require a wholesale rejection of sight? Could I, for example, find a way to truly embrace my blindness, even if I'd accept a miracle cure if one ever came along?

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Oscar recently asked me what my favorite TV show was. (We'd let him watch a few episodes of *Seinfeld*, and he'd loved it.) Before I could answer, he quickly added, "It's probably a show about blindness, right?" I assured him that my favorite show was definitely not about blindness (most TV shows with blind main characters happen to be, as far as I've seen, not great), but I liked that he had identified this tendency in me, the way that in the last few years I've become a sort of blindness collector. After we opened the floodgates on weekday movie nights during the pandemic, we watched the 1940 Technicolor epic *The Thief of Bagdad* together. Early in the film, we meet the main character, a blind beggar (he's an ex-sultan, cursed into poverty by an evil sorcerer). Oscar turned to me and said, simply, "*Blind!*"—as though he were pointing out an eagle that had just landed in our yard. I reached out to give him a fist bump. He was hesitant at first to return it: Why are we celebrating this again? But then he went with it; we're becoming a blind-positive family.

At one point in the movie, the sultan told a princess that she was the most beautiful woman he'd ever seen. Oscar asked, "Wait, how can he know that, if he's blind?" The film had been jumping back and forth in time, to before

and after the sultan's blindness, and we'd been following him in his sighted state for at least half an hour by that point. He'd engaged in all manner of activities—breaking out of an underground dungeon, exploring the bazaars of Basra—without any indication that he was visually impaired in any way. So how had Oscar missed that he was sighted?

I decided to take this not as a sign of Oscar's inattention, but rather as another feature of his positive attitude toward blindness. He hadn't yet absorbed the stereotypes of blindness that popular entertainments perpetuate, of the blind as exiled beggars, cursed, stumbling, and miserable. For him, maybe the sultan was simply blind like I am: clinging to a few degrees of residual vision that he used as best he could. It was perfectly natural to accept a blind character who ran around unfamiliar cities engaging in swashbuckling escapades. As I lose my vision, I want to cultivate this picture of blindness—in Oscar and Lily, in myself, and in the world—of a blind person who's an active protagonist in his own life. I haven't seen this vision in many representations of blindness in films, books, art, or TV, which tend to either mock and diminish blindness, or hold it up as a source of occult superpowers, or treat it with condescending pity—deploying it as a metaphor, rather than an everyday style of living. I found the image I wanted elsewhere: in the people I met out in the actual country of the blind, in the teeming variety of their stories of struggle, adaptation, and adventure.

Part I

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Phantom Limp

Seeing Stars

There are as many ways of being blind as there are of being tall, or sick, or hot. But the popular view has always conceived of blindness as a totality. The blind bards wandering the countrysides of ancient Japan, China, or Europe, the blind housed in asylums in the Middle Ages, all the pupils in all the schools for the blind from the Enlightenment onward, blind beggars and lawyers, war veterans and toddlers—in the eyes of history, as well as those of most of their contemporaries, they all saw nothing. Modern dictionaries still subscribe to this sense: blindness is the antonym of vision, and connotes a destitution of sight. What else could it mean?

Despite the poetic impulse to equate blindness with darkness, it's rarely experienced as a black veil draped over the world. Only around 15 percent of blind people have no light perception whatsoever. Most see something, even if it isn't very useful, by sighted standards: a blurry view of their periphery, with nothing in the middle, or the inverse—the world seen through a buttonhole. For some, scenes come through in a dim haze; for others, light produces a shower of excruciatingly bright needles. Even those with no light perception at all have little use for the popular image of blindness as darkness: the brain cut off from visual stimulus can still produce washes of brilliant color and shape. One blind man, whose optic nerve—the connection between the eyes and the brain—had been severed, described seeing a continuously swirling (and distracting) “visual tinnitus.” The Argentine writer Jorge Luis Borges, decades into his blindness, still saw color, which sometimes disturbed him: “I, who was accustomed to sleeping in total darkness,” he said,