

Blindness Is a Strange Country

Famous People Living with Vision Loss

Retinitis pigmentosa (RP) and how do people cope with gradual vision loss and what this means for their vision-related quality of life?

Redactor: Victoria Sara Dazin



Foreword

The sense of sight shapes our sense of self and our interaction with the world around us. Vision loss affects daily activities, quality of life and can have a substantial psychological impact.

Reactions to a diagnosis of a condition that leads to vision loss can be similar to being diagnosed with a chronic disease and vary according to prognosis, personality, perceived impact on life, and social and emotional support.

A diagnosis of conditions that lead to vision loss can be devastating and often affects mental health. Mental health effects include depression, anxiety, and stress-related worsening of vision.

Effects on identity include feelings of frustration with one's loss of function and with others' reactions to the disability.

I thought it appropriate to incorporate in this editorial a list of famous people - writers, politicians, scientists, artists, actors, and musicians - who suffered from the loss of sight but who did not let it stop its impact on the world around them.

Victoria Sara Dazin

Retinitis pigmentosa (RP).

Retinitis pigmentosa (RP) is a group of inherited eye conditions that cause permanent vision changes. Symptoms include a gradual loss of peripheral vision and difficulty seeing in poor light and, in most cases, eventually result in blindness. For some, loss of sight may occur over several years, whereas for others, loss of vision may be rapid. RP affects approximately 1 in 3,000 to 4,000 people and currently, there is no cure (except two very rare forms of RP).

By Dr. Gulcan Garip - 14 June 2018

Dr Gulcan Garip, Health Psychologist at the University of Derby Online Learning

<https://www.derby.ac.uk/blog/coping-with-gradual-vision-loss-living-with-retinitis-pigmentosa/>

Blindness Is a Strange Country.

What I'm finding as I lose my sight.

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 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 20 years ago, so I usually see my eye specialist every other year. 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.

There are as many ways of being blind as there are of being tall, 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.



*LEADING ASSUMPTIONS: Like Pieter Bruegel the Elder's 1568 painting *The Blind Leading the Blind* (pictured here), cultural depictions of blindness have been overwhelmingly negative, as though everyone who is not fully sighted spends their lives in this muddy, cold pit. Credit: Web Gallery of Art / Wikimedia Commons.*

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, was bothered for a long time at having to sleep in this world of mist, in the greenish or bluish mist, vaguely luminous, which is the world of the blind. I wanted to lie down in darkness.

The arrival of encroachment of blindness gives rise to a similarly dazzling range of experiences, an efflorescence of blind varietals. There are those born blind, with no visual memories, whose brains—including the visual cortices—develop using four (or fewer) senses to construct their view of the world. Those who become blind in early childhood often retain visual memories that can contribute

to an intuitive understanding of visual concepts. The late-blinded may have the most cognitive work to do, forced to relearn basic skills like orientation and information-gathering through new senses, long after their brains' developmental plasticity has hardened. Some late-blinded adults consciously struggle to preserve their storehouses of mental images, like art conservators touching up old and fading masterpieces.

Ancient Greek had one word for totally blind people, *tupelos*, and a different one, *amblyopia*, for “dull-sightedness.” Ancient writers shared our modern predilection for using blindness as a metaphor for heedlessness and various other moral, intellectual, or spiritual failings. The Greeks and Romans spoke of blind ignorance, blind leadership, and the blindness of wealth and love; the Old Testament described bribery blinding its recipient and the blindness of those who don't heed the voice of the Lord—those who “have eyes but are blind” (Isaiah 43:8).

Bruegel's 1568 painting *The Blind Leading the Blind* makes literal (and adds several participants to) the biblical proverb “If a blind man leads a blind man, both will fall into a pit.” The painting shows six blind men in a line across the canvas, each holding the shoulder or stick of the man in front of him. The blind guy at the back of the line looks like he's doing all right. As the eye travels across the composition, though, the aspect of disaster gradually increases: The faces contort with growing confusion and distress as the men grimace and stumble until we see the final blind man, arms and legs thrown wide, falling backward into the proverbial pit. The rest of the men are about to fall in on top of him.

Most disability histories describe the plight of blind people in these terms—as though they spent their lives in this muddy, cold pit. “Want and suffering were the rule rather than the exception and the blind were an economic liability,” Richard S. French observed in his representative study, *From Homer to Helen Keller*. “Toleration alone makes such abysmal beggary possible, and rarely does the blind man rise above it.” A tour through the Western canon offers a highlight reel of blind abjection: the pathetic stumbling of the cyclops Polyphemus, his eye pierced by Odysseus with timber that had been sharpened and then heated to a glowing red point; Oedipus taking long pins from his mother's garment and plunging them into his eyes (“The bloody pupils / Bedewed his beard. The gore oozed not in drops, / But poured in a black shower, a hail of blood”); the third-century B.C. biblical story of Tobit, who goes blind after a swallow shits in his eyes, believes his wife has become a criminal to support him, and prays for death. It wasn't until I'd returned home after my freshman year in college that my mom decided I'd been complaining about my eyes long enough that I should get them checked out by a specialist. She got me an appointment at an eye clinic at UCLA,

where I submitted to a long regimen of tests, including an ERG, which involves numbing your eyes and then attaching electrodes to your eyeballs to measure the amount of electricity your retinas are putting out in response to light. (It's like testing the charge on a battery, but the battery is part of your face...)

When I finally met with the doctor, a soft mustachioed man named Dr. Heckenlively, he confirmed what I'd gleaned from Wikipedia's great-uncle years earlier: I had "classic RP."

I could probably expect to maintain good vision during the day through my 20s and 30s. The night blindness would gradually become more severe, and my peripheral vision would erode. As I approached middle age, the degeneration would sharply accelerate. There is no treatment, he told me, but science is making great progress, so by the time I was *really* blind, in 20 or 30 years, there would hopefully be a cure. In the meantime, there were some vitamins I could take to try to prolong my useful vision. Did I smoke? Yes, of course, I smoked. I also had a radio show on the college station called *A Thousand Frowzy Steams*. Well, the doctor told me, I'd need to quit immediately-cigarettes are terrible for ocular health. Can you see stars? he asked.

This was something I'd already noticed: Starlight had become too dim for me to register. It was also the detail that brought it all home for my mom. She sat up straight: "You can't see stars!"

Afterward, we visited a museum downtown, where we saw a show of Richard Serra's *Torqued Ellipses*-huge steel sheets rolled into standing curves set within one another, creating open tunnels. Wandering through these brief mazes, each with only two or three turns to make inside, made it feel like the shape of the whole world had changed; the world itself became a torqued ellipse, with only a strip of the outside splashing in. I felt at once claustrophobic and expansive.

BY ANDREW LELAND

Andrew Leland is a writer, audio producer, editor, and teacher whose work has appeared in *The New Yorker*, *The New York Times Magazine*, *McSweeney's Quarterly*, and others. He is an editor at *The Believer* and hosted and produced the podcast *The Organist*; *The Country of the Blind* is his first book.

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Lead image: fran_kie / Shutterstock

A Legally Blind Photographer, Finger Painter, and Writer.

I'm a legally blind photographer, finger painter, and author of Kindle e-books for children, teens, and adults. The arts have been a big part of my life from an early age, but having a progressive eye disease, called Retinitis Pigmentosa, or RP, made it hard to keep doing these things.

When I could no longer sketch, I discovered that I could finger paint. When I could no longer finger paint, I discovered that I could take fine art photos like my hero, Ansel Adams, with the help of a point-and-shoot digital camera set on auto, a 47-inch computer monitor, my former art education, and my remaining vision.



They say you're lucky to have had one dream come true in life. I've had many. I earned two degrees and became a social worker, a mother, a writer, a finger painter, and a photographer. Being a legally blind photographer, artist, and writer has its challenges, but I find if you push yourself a little, good things can happen.

Tammy Ruggles – A Legally Blind Photographer, Finger Painter, and Writer

Posted on December 12, 2016, by LODI360 Editor

Tammy Ruggles' Website

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<https://eyesight.org/2016/12/12/tammy-ruggles-a-legally-blind-photographer-finger-painter-and-writer/>

Famous People Living with Vision Loss

With all the recent news about Rosanne Barr's vision loss due to age-related macular degeneration (AMD) and glaucoma, I thought it would be interesting to see other famous people with vision loss who didn't let it stop their impact on the world around them.

Authors

Harper Lee (1926-) – Best known for her 1960 Pulitzer Prize-winning book *To Kill a Mockingbird*, she has been diagnosed with Age-related macular degeneration (AMD). Her second novel, *Go Set a Watchman*, which was written before *To Kill a Mockingbird*, will be published this July.

John Milton (1608-1674) – English poet who wrote the poem *Paradise Lost*, among others, and became blind at the age of 43.

Alice Walker (1944-) – American author and activist who wrote *The Color Purple* which won the Pulitzer Prize and the National Book Award in 1983. She was blinded in one eye as a child when shot with a BB gun.

Joseph Pulitzer (1847-1911) – American newspaper publisher who established the prestigious journalism award, the Pulitzer Prize. He became blind at the age of 42 due to a retinal detachment.

James Thurber (1894-1961) – American humorist who switched his attention from sports to writing when his brother shot him in the eye with an arrow while recreating the legend of William Tell shooting the apple of his son's head.

James Joyce (1882-1941) – Irish novelist and poet who had numerous eye surgeries for various conditions starting with iritis.

Stephen King (1947-) – American author of contemporary horror, supernatural fiction, suspense, science fiction, and fantasy. He has been diagnosed with AMD.

Leaders

Horatio Nelson (1758-1805) – British naval admiral lost an eye as a young seaman. He was said to have used this to his advantage by raising his telescope to his blind and then claim not to see the flags of surrender being raised by enemy ships.

Thomas Gore (1870-1949) – Blinded as a child, he became the first senator from Oklahoma and the first blind member of the US Senate.

Steve Wynn (1942-) – A well-known business leader having helped build up Las Vegas, and the owner of The Wynn and The Encore Resorts, he was diagnosed with retinitis pigmentosa in 1971 and declared legally blind in 2010.

David Alexander Paterson (1954-) – He was the first African American Governor of New York and the second legally blind governor of any state, after Bob Riley of

Arkansas. Paterson became blind at the age of three months when an ear infection spread to his optic nerve.

Willie Brown (1934-) – He spent over 30 years in the California State Assembly and served as the first African American Mayor of San Francisco for eight years. He has retinitis pigmentosa.

Hellen Keller (1880-1968) – She was an American activist, lecturer, and author. She was the first deaf/blind person to graduate from college. At the age of 19 months, she came down with an infection that left her deaf and blind. She inspired the Lions Clubs International to become the “knight of the blind,” leading them to focus their community service efforts toward vision-related causes.

Science & Medicine

Dr. Jacob Bolotin (1888-1961) – Was the first congenitally blind person to receive a medical license. This Chicago physician’s specialties were diseases of the heart and lungs.

John Glenn (1921-) – He was the first man to orbit the earth in 1963 on the Friendship 7 mission. He suffers from glaucoma.

Joseph Plateau (1801-1883) – Belgian physicist who invented an early stroboscopic device, the phenakistiscope, in 1836 that allowed still images to create an animated effect. It eventually led to the development of cinema. He performed an experiment in which he gazed directly into the sun for 25 seconds, leading to his eventual blindness.

Artists

Georgia O’Keeffe (1887-1986) – Best known for her paintings of enlarged flowers, New York skyscrapers, and New Mexico landscapes, she was recognized as the “Mother of American modernism”. In 1972, O’Keeffe’s eyesight was compromised by age-related macular degeneration (AMD), leading to the loss of central vision and leaving her with only peripheral vision. She stopped oil painting without assistance in 1972 but continued working in pencil and charcoal until 1984.



Claude Monet (1840-1926) – A French impressionist painter who had cataracts that blurred his vision and caused a severe loss of color perception. After complaining about his cataracts for ten years, he had cataract surgery in 1923. Those paintings before the surgery have more of a reddish tone, while those painted before his cataracts and after the surgery show more blue tones.

Edgar Degas (1834-1917) – A French artist known for his paintings, sculptures, prints, and drawings. He had a chronic and progressive retinal disease that made him sensitive to light and caused him to lose his central vision. Frustrated by these

limitations he switched to oil pastels because less precision was needed. He finally resorted to sculpting to be able to utilize his sense of touch and feeling to continue to create art.

Actors

Johnny Depp (1963-) – Known for his many movie roles, Depp doesn't let his vision loss stop his career. Besides correcting his blurred vision, the tinted lenses of the glasses he wears also help with Meares-Irlen's 'visual stress' syndrome, which causes dizziness, discomfort, and eye pain. He is also nearly blind in his left eye.

Issac Lidsky (1979-) – A child actor known for his part in the *Saved by the Bell: The New Class* TV series, he was diagnosed with retinitis pigmentosa (RP) at 13 and was completely blind by 25 years of age. He changed the course of his career, becoming a lawyer. He was a law clerk for Justices Sandra Day O'Connor and Ruth Bader Ginsburg in 2008-09, making him the first blind US Supreme Court clerk.

Jon Weller (1975-) – A TV actor who has performed on many shows, he is best known for his recurring role of toxicologist Henry Andrews on *CSI: Crime Scene Investigation*. He has been diagnosed with RP.

Dame Judith Dench (1934-) – A actress has had a long career in theater and film, receiving many awards including ten BAFTAs, six Olivier Awards, two Screen Actors Guild Awards, two Golden Globes, an Academy Award, and a Tony Award. She is well-known for the part of M in the James Bond series of films. In 2012 She announced that she has age-related macular degeneration (AMD), but has no intentions of slowing down. Scripts are now provided to her in a larger font.

Musicians

Ray Charles (1930-2004) – He was born with congenital glaucoma which resulted in blindness by the age of 7. This American singer, songwriter, musician, and composer, received multiple Grammys, was inducted into the Rock and Roll Hall of Fame, and was a Kennedy Centers Honoree.

Stevie Wonder (1950-) – He is a singer-songwriter, multi-instrumentalist, and record producer who signed with Motown Records at the age of 12. He has won 25 Grammys and received the Grammy Lifetime Achievement Award. He is blind due to retinopathy of prematurity due to excessive oxygen in his incubator when he was born.

Andrea Bocelli (1958-) – An Italian classical tenor, he was born with congenital glaucoma, but lost his vision at the age of 12 following a soccer accident in which he was hit in the head. He started playing piano when he was six, also learning the saxophone and flute. Bocelli has recorded fourteen solo studio albums, of both pop and classical music, three greatest hits albums, and nine complete operas, selling

over 75 million records worldwide, making him one of the best-selling music artists of all time.

Ella Fitzgerald (1917-1996) – An American jazz singer often referred to as the First Lady of Song. She also appeared on TV and in movies. She won 14 Grammy Awards, the National Medal of Arts, and the Presidential Medal of Freedom. She was diagnosed later in life with diabetic retinopathy due to her advanced diabetes, which also cost her both legs.

Do you know of any creative famous people You could add to this list? Please share them below in the comments.

Famous People with Vision Loss

By Susan DeRemer, CFRE

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