



Seeing Without Sight: Living with Retinitis Pigmentosa in a Visually Demanding World

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DESCRIPTION

Retinitis pigmentosa is not just a condition of the eye; it represents a continuous shift in how people experience the world around them. Those diagnosed often encounter a gradual loss of vision, starting with difficulty seeing at night and narrowing of their peripheral field. But the impact of this disorder extends far beyond retinal changes. It transforms how individuals interact with everyday life, how they navigate public spaces, and how they engage in tasks many take for granted.

This group of inherited disorders affects the retina, specifically the light-sensitive cells responsible for transmitting visual information to the brain. Over time, these cells begin to deteriorate. What begins with mild inconvenience—bumping into objects in low light or struggling to see at dusk—often evolves into more significant challenges. The field of vision shrinks slowly, creating what is sometimes described as tunnel vision. While some retain limited central sight into adulthood, others experience a more rapid decline that may result in near-complete blindness.

From a clinical standpoint, retinitis pigmentosa can be diagnosed through retinal imaging, visual field testing, and electroretinography. These tools allow specialists to observe functional changes and track progression. Despite advances in imaging and diagnostics, the personal perspective of living with such a condition is rarely captured in clinical reports. Numbers, graphs, and charts do little to convey what it's like to wake up each morning with slightly less vision than the day before.

People who live with this disorder face barriers that are not always visible. These include assumptions made by others about their abilities or limitations, and the often uncomfortable process of needing to disclose their condition in environments where it may not be obvious. Many individuals find themselves in situations where they must explain why they need assistance despite appearing visually able in well-lit conditions. These misunderstandings can result in feelings of frustration, exclusion, or being misjudged.

Another aspect that deserves attention is the emotional toll. Vision is not only functional but also tied to identity, confidence, and social participation. Losing this sense affects far more than navigation or reading; it touches relationships, self-image, and even the type of employment opportunities available. While some adapt well with the support of family or specialized services, others struggle in silence, often because they don't want to appear as if they are giving up or becoming dependent.

There is a widespread perception that vision loss automatically means helplessness. This perspective often leads to over-accommodation or, paradoxically, a lack of necessary support. For those who live with this diagnosis, independence is not an abstract concept but something they constantly work to maintain. It requires careful planning, adjustment of habits, and a willingness to approach tasks differently. What once took a few seconds might take five times as long. Tasks such as preparing meals, shopping, or crossing a busy street can become complex, requiring not only alternative techniques but also a constant awareness of personal limitations and environmental risks.

CONCLUSION

Modern technology has created new opportunities for those affected, such as screen readers, audio navigation tools, and magnification software. But access to these tools is uneven, and not everyone finds them easy to use. Moreover, technology does not solve all problems. Human interaction, understanding, and social design remain critical. Sidewalks, public transportation, workplace expectations, and digital platforms are often developed without consideration for those who see the world differently.

One often overlooked element is how individuals with retinitis pigmentosa develop a strong reliance on other senses. Sound, touch, and spatial memory play a significant role in making sense of surroundings. Many people report that they become more attuned to tone of voice, changes in flooring, or the scent of places and people. These adaptations are not sudden but form gradually, shaped by necessity and repeated experience.

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