

Editorial ► What Can We Learn from Patient H69?

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I am not sure what it was about the book *Patient H69* by Vanessa Potter that spoke to me as I was searching for a new pleasure book to read, but I am so thrilled that I chose it. Not only did I learn about a new condition, neuromyelitis optica (NMO), but I found a new appreciation for my patients and their perception of their vision. The other amazing thing about reading this book was that literally the day after completing it, I was covering in our Low Vision Service, and a patient came in with a history of this very condition. I have to admit that I sounded amazingly brilliant that day. I even talked to the patient about the book and how her vision was different from the author's.

Neuromyelitis optica, or Devic's disease as it was previously known, is a central nervous system disorder that primarily affects the optic nerve and the spinal cord. If the eyes are impacted, it produces an optic neuritis. NMO occurs when your body's immune system reacts against its own cells in the central nervous system, mainly in the optic nerves and spinal cord, but sometimes in the brain. The overall condition is now known as neuromyelitis optica spectrum disorder.

The cause of neuromyelitis optica is usually unknown, although it may sometimes appear after an infection, or it may be associated with another autoimmune condition. Neuromyelitis optica is often misdiagnosed as multiple sclerosis (MS) or perceived as a type of MS, but NMO is a distinct condition. This was the case with the patient that I personally saw with NMO. Even though she was diagnosed almost 20 years prior to our visit, she only recently had a change in diagnosis from MS to NMO.

Neuromyelitis optica may cause blindness in one or both eyes, weakness or paralysis in the legs or arms, painful spasms, loss of sensation, uncontrollable vomiting and hiccups, and bladder or bowel dysfunction from spinal cord damage. Attacks may be reversible but can be severe enough to cause permanent visual loss and problems with walking.

You can read more about NMO at the following websites; all are extremely reliable sources.

<http://bit.ly/2vXaCqT>

<http://bit.ly/2wB2IRW>

<http://cle.clinic/2hRhRLR>

The most crucial aspect of this book was that it provided a first-hand description of the impact of the vision loss, improvement, and the battles waged to get where the author is currently.

This first quote is very early in the book, when the author's symptoms began. I was drawn to it since we treat so many patients post-brain injury that probably have issues describing their symptoms and feelings. How much are we missing that they can't describe?

Messages clearly aren't getting through. Why isn't there a universal word to describe this bizarre feeling? Maybe that is the problem; for what I feel is definitely more sensation than anything concrete, and that makes it all the more impossible to explain. Feelings are so infuriatingly subjective, and my unusually vivid descriptions are falling on deaf ears. I need someone to crawl inside my head and see what's going on for themselves—then maybe they could describe it.

After several days, the author's vision loss has become significant. Hour by hour she loses clarity and field of vision. The book is ripe with descriptions like this in which the author opens her heart and displays her fears for the world to read.

Faces are starting to disappear, and I feel a huge sense of loss. I miss the compassion and understanding that eye contact allows me.

I suppose he believes these are silly unnecessary facts, but to me they provide texture and shape. These little details are keeping my ability to see alive, albeit inside the confines of my head.

Perhaps the most interesting descriptions, well to me at least, occurred when her vision was improving. The detail she gives and the descriptions she offers are stunning. She owes this detail and awareness to her background in the visual arts.

Over the last few hours I have begun to identify the shadowy patches on the bottle as letters. Dark silhouettes float eerily against the pale background when I hold the bottle centimetres from my face. Not understanding what my vision is seeing, they all ask me what the letters

are, and I have to wave their nonsensical questions away. This isn't about seeing like they see; this is about sensing that something is there. I am using different parts of my brain to register this information ... I try and tell them I'm not at the seeing stage yet, but they scratch their heads.

'So, if you have 20/20 vision--you're back to normal then?' No, it's as if I look through a dirty windscreen, as if all the colour has drained away and daytime looks like dusk.' 'Hmm.' 'There's this disturbance--almost like a shimmer.' 'A shimmer? So things move?' 'Not exactly. Well yes, sometimes things shudder to me. But we don't really know why that is. It could be something called a microsaccade.' 'Oh it's complicated.'

Yes, NMO is a pretty rare condition, but the point was not to bring the condition to your attention. My goal was to draw your attention to your patients: how they describe their vision, symptoms, and changes that have or may occur. In the healthcare universe, being able to stop and smell the roses, aka listening to the patient, is becoming increasingly challenging. If it were not for some special caregivers and doctors, it is unknown what the visual and physical outcome would have been for Patient H69. They stopped and listened; they made all the difference to this patient. I am asking you to do the same.



Listen to Patient H69 tell her own story as part of the TED talks program. <http://bit.ly/2uxDH8U>

EDITOR'S NOTE: In *OVP* Volume 5, Issue 3, the article, *Corectopia: Facilitating a Preferred Retinal Site/ Preferred Retinal Locus: A Theory on Enhancing the Potential for Reorganization of Visual Processing in Those with Macular Degeneration/Absolute Central Scotoma*, by Lawrence A. Routt, Sr., OD, has been updated. Please see the updated version at <http://bit.ly/Routt>.

“MFBF” Matching Game

The MFBF Matching Game (also known as Red Red Rock Game) was developed as an activity for use in all aspects of vision therapy. The goal of this activity is to serve as a bridge from monocular to binocular activities, improving efficiency of the patient's use of accommodative and binocular systems. This game offers 7 levels of exercises based on the age and capability of the patient.



www.oepf.org/MFBF_Game