

## A Post Optic Neuritis World: Patient H69's Story

Vanessa Potter

Waiting to go on stage at the Guthy Jackson NMO (Neuromyelitis optica) conference in March 2018, held in the imposing ballroom at the Hilton LAX hotel, I was visibly trembling. This international patient day had been arranged to discuss the latest medical developments in the field of NMO. Also known as Devic's disease, NMO is a rare relapsing neurological autoimmune condition that commonly affects both the optic and transverse nerves, causing sight and mobility loss. It's also the disease I was diagnosed with after I woke up blind and paralysed one morning in 2012.

Even years after my recovery, I still had residual sight loss. To compensate for this I had surreptitiously mapped out my route onto the enormous stage during the morning's

*Correspondence regarding this article should be emailed to Vanessa Potter, at [patienth69@live.com](mailto:patienth69@live.com). All statements are the author's personal opinions and may not reflect the opinions of the College of Optometrists in Vision Development, Vision Development & Rehabilitation or any institution or organization to which the authors may be affiliated. Permission to use reprints of this article must be obtained from the editor. Copyright 2019 College of Optometrists in Vision Development. VDR is indexed in the Directory of Open Access Journals. Online access is available at [www.covd.org](http://www.covd.org).*

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rehearsals. Mentally measuring the height of the steps (normal stair height) I scanned the surface and dimensions of the stage. It was covered with a white matte fabric that thankfully had no obvious shadows. However, looking helplessly over at the perspex lectern, set out for me to rest my notes on, I sighed. Perspex, really? Glass, Perspex, indeed anything transparent creates a kaleidoscope of problems for me. The reflections that bounce back off the surface often display a double or triple image. This means I often don't know where one objects starts or ends; or even what is real. Grimacing at the lectern, I conceded that I would be holding my notes that day.

I had been invited by The Guthy Jackson Charitable Foundation to talk about my NMO story and the book I published about my sight loss. The charity was established in 2008 by Victoria Jackson following her daughter's diagnosis with the illness. As an NMO patient I knew first hand the devastating effects this condition could have, yet I still considered myself one of the lucky ones. Sitting in the audience were a mixture of men and women in wheelchairs and in some cases, with well-behaved guide dogs at their sides. I could walk out on stage unaided, so I knew I was fortunate.

The moment I looked out at that sea of faces, I realized something that none of the eminent and expert doctors there could know. I knew what the people looking up at me saw. More importantly, I knew what they didn't see. The mishmash messed up visual landscape that we collectively inhabit is unique. We may know where we are, but we don't always recognise our environment. And, explaining that to eye-care specialists is one of the hardest challenges a patient has. We navigate intuitively, but with a conscious effort that normally-sighted people could not imagine. There is no obvious view, no visual picture that is taken for granted – it is all worked out and intimately mapped in a discreet, yet pragmatic manner.

During the Q&A session after my talk a woman stumbled whilst trying to describe her vision to the room. As her voice trailed away I felt her frustration ripple across the room. Waving at the stage, I admitted my own careful planning earlier, describing how I'd mentally mapped my way onstage and how I'd blocked out the cacophony of irregular lines and colours around me. Pointing at a row of flags behind the stage, I explained these were a great example of visual overload. Those of us with reduced sight require flat, continuous tones and shapes, predictable lines and reliable surfaces to orientate ourselves. The flags were literally too much to take in; they were exhausting and overburdened my brain. But, the real elephant in the room was the carpet. Oh the carpet! We patients couldn't avoid that. Pointing at the whirling, swirling lilac and crimson maze that was like walking on a sea of serpents, my fellow patients erupted in united cheers. A visual hazard for all of us, we had all unconsciously navigated it.

The carpet may have caused error messages inside our brains, but we didn't talk about it. It was one of the few times in my life when for once, vision became a communal and shared experience. On the whole, seeing is a solitary act. We may stand in front of the same sunset or flowerbed, but how we place it into its environment, the depth of color, the detail, the feelings it imbues – is entirely personal. When vision goes wrong, it becomes even more difficult to explain. The very rules of seeing are rewritten. It is vision's very subjective nature and the difficulties patients have in describing it, that causes problems when identifying and treating visual disorders. In that one moment, it was these difficulties and the clever tactics that we had all employed to overcome them, that connected us.

Back in 2012 it took just three days for me to lose my sight completely. Optic neuritis is an inflammation of the optic nerve and can have a number of causes. It is commonly associated with Multiple Sclerosis and indeed with other

autoimmune conditions, but it can also be caused by infection. The most identifiable symptoms are vision loss, in particular color loss and pain when moving the eyes. It also commonly only affects one eye, so as I experienced complete bilateral sight loss, it would appear I was not a common case.

Having suffered optic neuritis I know that my visual landscape has changed and that I have to engage with the outer world in new ways. One of my strategies is variety. My visual system is greedy; it wants stimulation, but stimulation in small doses. I walk different routes with my children to school, I avoid my vision becoming lazy and using old memory maps to navigate by. In the same way I read books on visual processing, I absorb new ways of seeing. Vision is habit. This is something you begin to realise once you have lost it. As humans we are routine based. We love regularity and our visual system is drawn to lines and predictable outcomes. It's good to mix up life, to throw in a challenge or an anomaly. In this way I throw in change for my visual system too. It is within the gaps of our knowledge that we grow – it's the very difficulties I encounter that translate eventually into resilience. We don't perhaps appreciate vision as a resilience tool, but it is. The more I see, the more I can do. And, that means the more I can get my children around too. The uncertainty that an optic neuritic episode can leave a patient with, can shrink their world very quickly.

As I write this article sitting in a South East London cafe, my daughter is at her drama class. My habit is to come and work for the three hours she is there. An old gentleman comes in every Saturday at 11am. Like clockwork, the staff put a reserved sign on his table (corner, by the window) as they know he will be there come rain or shine. He even has the same greeting – a short wave of his stick, a nod of the head. Such are our habits. I have to fight this desire for normalcy and sameness; I have to force my visual system to

accept change. That could be driving down new streets, or making myself go to festivals. Curbs that blend seamlessly into the road, or cats that hide behind postboxes, I force myself to see it all. On high contrast sunny days, the black-and-white criss-cross shadows both dazzle my brain and illuminate the road. Grey misty days disguise the sidewalk, merging it into the road in front of me. The pedestrians, bikes and garbage bins. The discarded carpet I wasn't expecting to be sticking out. It is all of these incidental objects that help rebuild my processing ability and chip away at that fear.

These days, I don't recall visual information in the way I used to. I have to adapt to not knowing where I have been and accepting I couldn't navigate my way back there again. Satellite navigation is my saviour. Visiting Saint Georges hospital in London for regular treatment a few years ago, I navigated not by the common visual cues, but by looking for Snappy Snaps and Barclays Bank. I knew that the street I needed was opposite these shops. I can't recall this route inside my mind now, nor can I fully visualise the shops in the way I could have done before. I have to follow these new rules of orientating every time I go. I no longer have a reliable internal mapping system. I can't conjure up the many landmarks, street names, houses and trees within a cohesive whole. My visual recall now is separate squares of information, a patchwork quilt of visual data, road signs, trees or traffic lights that I struggle to piece together.

I have taken to photographing what I can't see – the gaping holes in my vision. I note when a step merges into the one below, or when I have to stare at an object in order to identify it. These photos show the glitches, the moments when my inner wiring comes loose and lets me down. It is by offering up the cracks in my perception, this faulty wiring, that allows insights into the life of a post-optic neuritis patient.

Sitting in my local cafe recently, a object in my peripheral vision caught my attention.

Turning around, I stared at an orange shape that I could not identify as either a coat, small dog or bag. It turned out to be a plastic shopping bag, strangely inflated and not looking like a Sainsbury's shopping bag 'should look like'. I was aware that part of my identification process was waiting for it to move; or not.

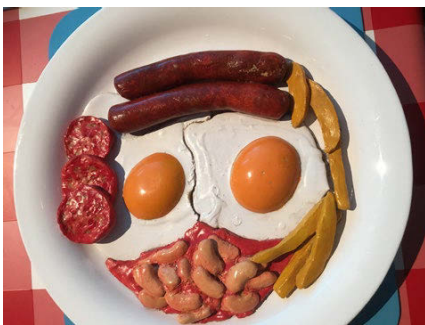


When we were driving in LA, my husband saw a poster and commented on it. For a beat or two I had no idea what he was talking about. A Vampire movie? All I could read was 'Santa Clarita Diet'. How did he get Vampires from that? It was only when he shot me a quizzical look that I realised I hadn't seen the faces next to the text. I know why I didn't 'see' the faces of course. It was nothing to do with the size or clarity of the image, it was purely because that section of information was in a separate visual box. My brain had blended the faces with several bushy trees situated directly behind the poster (I took this image later on). The couple's faces were tonally the same as the foliage, meaning that on a contrast level, they were very similar. My brain likes nice high contrast and so zooms in on stark examples of this – like the letters, even though they are smaller and in some ways less visible than the faces. This is the nature of seeing the world like

a fragmented jigsaw puzzle, and processing each piece individually.



At a local exhibition educating children on their sensory system, an exhibit illustrating the way our vision allows us to stay safe (in this case from mouldy food) I failed the test completely. I still cannot tell which plate of food has the mouldy food on it. These days my children are my mould police, squealing if the bread has gone green and Mummy is about to toast it.



On the whole, I hide my visual loss very well. Occasionally it catches me out, but even then I find humour or distraction can divert any long lasting effects. At my daughter's sports day recently she saw I was scanning the four hundred girls there, trying desperately to locate her. Seeing my invisible struggle, she rushed over, risking the wrath of her teacher. 'Mummy I'm under the second gazebo, I'll wave when I go back.' At age ten, she is now primed to spot my surreptitious scanning and my not-so-nonchalant orientating in unfamiliar situations. She knows I have missed her in swimming galas, even though I was trying to see her. Now she has strategies of her own. Photographing my son at her sports day I did a double take (and indeed do the same double take every time I see this picture) as his blue hood blends so much into the umbrella behind him that he becomes unidentifiable. I can only really make sense of this image because I know how and where (and the context) of where it was taken.



This is an all too common occurrence. Living with the residue of optic neuritis, I often find myself trying to manage these situations; often feigning absentmindedness, distraction

or some other more acceptable reason for missing huge chunks of visual data. It was at the conference in LA that I realised for the first time that I am not alone in that.



49 year old Jeanette McCourt has lived in Arizona for the past 20 years, and suffers from NMO and the after effects of optic neuritis. In this image she took as a passenger in a car, she describes the lines in the road as floating up above the ground. She felt like she was wearing 3D glasses, except of course she wasn't. This visual phenomenon is explained using the SILO response. If some visual information such as contrast and context is reduced, then the brain can start to take visual cues from the eye muscles instead. This then overrides the limited available sensory data. In Jeanette's case, her brain assumed incorrectly and posed a view of the world that she knew must be inaccurate.

The side effects of poor contrast sensitivity and low color are many — and often affect my assumptions of what I believe I should see. Of course we all have innate assumptions that help construct our visual landscape, but those rules of seeing have changed for me, so in turn I have to adapt. I live with the knowledge

that any complex environment will inevitably swamp my senses. Part of my coping strategy is first knowing my limitations, identifying the situations that are likely to cause me discomfort and telling those around me. It's easy for my family and friends to forget my visual loss, particularly when outwardly I appear so capable. Half of managing sight loss is not the impairment itself, but the people you find yourself with and environments you find yourself in.

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## CORRESPONDING AUTHOR BIOGRAPHY:

**Vanessa Potter**

London, England, United Kingdom

Before becoming a self-experimenting science communicator, Vanessa Potter spent 16 years as an award-winning broadcast producer working within the London advertising industry. In 2012 she lost her sight due a severe illness called Neuromyelitis Optica Spectrum Disorder. Following her recovery, she collaborated with neuroscientists at Cambridge University to design an interactive immersive exhibition, based on her therapeutic use of meditation, and gave a TEDx talk about her experiences in Ghent in 2016. She documented her blindness and recovery in her memoir, *Patient H69: The Story of My Second Sight*, which was published by Bloomsbury Sigma in 2017 and won *The Times* best memoir of 2017. She's the recipient of an Inspiring Woman award, and has written pieces for *Mosaic Science*, *The Telegraph* and *Marie-Claire*. Vanessa lives in South-East London with her husband and two children.