

Managing Visual Snow and Tinnitus: A New Kind of Normal

By Matthew Renze

On February 7, 2014, I went to sleep with a mild headache, but otherwise was in good health. When I woke up the next day, I experienced the first set of strange symptoms that would change my life forever.

It started with brain fog. I had difficulty thinking, reasoning, and concentrating. I also felt a tingling sensation, like pins and needles, all over my body.

The following day, I woke up to a constant ringing in both ears. In addition, I now had a strange static across my entire field of vision, similar to the static of a slightly out-of-tune analog television.

Over the next few days, I began to experience a series of other unusual visual, auditory, and tactile symptoms, including seeing afterimages and other visual artifacts, difficulty with loud noises, and fine tremors in my hands and feet.

All of these symptoms persisted, except for the brain fog, which fortunately went away after a week or so.

Searching for Answers

On the third day, I scheduled an appointment with my general practitioner. He ran the standard battery of tests, but everything came back normal. Out of options, and unsure of where to send me next, he referred me to the Mayo Clinic in Rochester, Minnesota.



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I spent two weeks at the Mayo Clinic getting a wide variety of tests from some of the top specialists in the world. However, all my tests came back normal. Without an official diagnosis, they concluded that I was most likely experiencing something they referred to as a Central Sensitization Disorder (CSD).

They didn’t know what caused it, and there was no known cure. So,

they suggested I learn how to manage my symptoms, wait it out, and see if things improved over time. They also provided a temporary prescription for anti-anxiety medication to help with managing the stress that I was under until I could learn how to manage the symptoms on my own.

I began researching CSD to help my recovery plan. While researching, I discovered a recently published ar-



Credit: Heather Witbe

Matthew Renze celebrates his finish of RAGBRAI 2017, an annual 450-mile bike ride across Iowa.

ticle on a rare neurological condition, referred to as visual snow. The article described visual snow as “continuous tiny dots in the entire visual field, similar to the noise of an analog television.”¹

The article went on to describe Visual Snow Syndrome as a collection of symptoms, including palinopsia (seeing afterimages), entopic phenomena (excessive floaters, blue-field entoptic phenomena, and spontaneous photopsia), photophobia (sensitivity to bright light), and nyctalopia (impaired night vision).

In addition, one of the most interesting findings reported in this article, and in subsequent studies^{2,3}, was that approximately 63 percent of visual

snow patients also reported continuous bilateral non-pulsatile tinnitus.

The description of the symptoms almost perfectly described what I had been experiencing over the past several months. I finally had an explanation for my cluster of unusual symptoms. In addition, I now understood why my doctors had never heard of the condition.

Learning to Manage Symptoms

As you can imagine, this combination of symptoms would be quite difficult to manage. Dealing with bothersome tinnitus on its own is difficult enough. However, just imagine having this same annoying noise in *both* your vision and sense of touch all day long. You essentially have a recipe for disaster on your hands.

My struggle to cope with the sensory noise led to considerable stress, anxiety, sleep issues, difficulties concentrating at work, and eventually depression. However, the Mayo Clinic provided me with the tools that I needed to learn to manage these symptoms.

First, I was able to identify factors that made my symptoms worse. My symptoms always are present to some degree every day. However, certain things make them noticeably worse, including stress, lack of sleep, having a cold or the flu, and excessive computer use. So, I tried to minimize

these factors as much as reasonably possible to keep my symptoms in check.

Next, I started eating a much healthier diet. I noticed that foods with a lot of salt or sugar seemed to make my symptoms temporarily worse. So, I eliminated these foods from my diet. In addition, I ate more of the foods known to improve overall health. I did this to give my body and brain the nutrition they needed to repair and stay healthy.

I began exercising more. This helped tremendously with managing stress, anxiety, and depression. I

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also began practicing yoga to learn to manage my response to stress. Yoga teaches you how to calm your body and mind when confronted with stressful stimuli.

What helped me the most with managing my symptoms, however, was meditation. Like yoga, meditation teaches you how to calm your sympathetic nervous system in the face of painful or pleasurable thoughts, emotions, and physical sensations.

This is done through focused awareness of breath and monitoring of thoughts, emotions, and bodily sensations. Over time, you learn to minimize your emotional response to these sensations. In addition, it helps

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with concentration, maintaining non-judgment, and minimizing cravings and aversions.

However, learning these valuable skills took the right instruction and a lot of practice. To learn how to meditate properly, I took a 10-day course on Vipassana meditation.⁴ This helped enormously to get me on the right path with my daily practice.

In addition, I watched a 12-hour video lecture series on The Science of Mindfulness.⁵ The lectures are taught by Ron Siegel, professor of Psychology at Harvard University. This helped me to understand scientifically how meditation was changing my response to stress.

I also record biofeedback and neurofeedback data from each of my daily meditation sessions. This has allowed me to track the progress of my meditation practice over time. As a result, I can objectively see how meditation has created a significant difference in my ability to respond to stressful stimuli.

For me, a healthy diet, exercise, and mindfulness practices have allowed me to turn bothersome symptoms into manageable symptoms. As a result, I have been able to manage my symptoms without medications for several years now. So, while I may have to deal with my symptoms

every day, I am very happy to report that I am no longer *suffering* from my symptoms.

The path from where I started to where I am today *was not* an easy path to walk. We imagine our recovery will be like a gradual staircase, leading from where we currently are to where we need to be. It seems deceptively simple — just keep climbing step-by-step each day until you're at the top again.

However, the reality is that the path to recovery is a very jagged mountain range with more ups and downs than we could ever imagine. Over time, though, you begin to realize that you are having progressively more good days than bad days. Finally, you look back to see where you once were and realize how far you've actually climbed in the process.

A New Kind of Normal

Today, my life has returned to a new kind normal. I still have all of my symptoms; however, they are now much more manageable. In addition, my symptoms no longer cause me stress or anxiety like they did in the past. Essentially, I've learned to coex-



Matthew Renze at Yoga in the Park, Ankeny, IA.

ist with them as just another part of my day-to-day life.

While it may seem counterintuitive, in some ways, this very difficult experience has been one of the best things to ever happen to me, because I've applied the lessons it taught me to my daily life.

First, the experience taught me to appreciate what is truly essential in life and to make the most of it. As a result, I've taken several personal and professional risks, that prior to this experience, I would have been too afraid to take. This has led to a new relationship, rapid career growth, spending more time doing what I love, and getting to travel the world.

Second, I now have significantly more empathy for those who are suffering in their own lives. Prior to this experience, it was hard for me to relate to people who were going through difficult situations with their physical and mental health. However, I now am better able to empathize and help others who are currently struggling, like I once was.

Third, this experience taught me how to leverage mindfulness practices, like meditation, to better cope

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with the stress of day-to-day life. This has had an enormous impact on my ability to deal with difficult situations, meet tight deadlines, and speak to large audiences.

However, the most important lesson I learned is easy to say out loud, but much more difficult to understand. I now know it is possible to be in mental, physical, or emotional pain, but to not be suffering from that pain. This is because suffering is how we respond to pain. 



Matthew Renze is a data science consultant, author, and international public speaker. To raise awareness of Visual Snow Syndrome, he's presented on the topic at medical conferences, written articles in peer-reviewed journals, and created online videos providing information to help others with the condition. For more information, visit his website at: <http://www.matthewrenze.com>

To view Matthew's presentation on his story and the relationship between tinnitus and visual snow, see: <https://youtu.be/jUnMBd0zySo>

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Matthew will be presenting on this topic at the first-ever Visual Snow Conference in San Francisco on May 5, 2018:

<https://visualsnowconference.com>

- 1 Schankin CJ, Maniyar FH, Digre KB, & Goadsby PJ. 'Visual snow' — a disorder distinct from persistent migraine aura. *Brain*. 2014; 137 (5): 1419-1428. <https://doi.org/10.1093/brain/awu050>
- 2 Schankin CJ, Maniyar FH, Sprenger T, Chou DE, Eller M, & Goadsby PJ. The Relation Between Migraine, Typical Migraine Aura and "Visual Snow". *Headache: The Journal of Head and Face Pain*. 2014; 54(6):957-966. <https://www.ncbi.nlm.nih.gov/pubmed/24816400>
- 3 Lauschke J, Plant G, & Fraser C. Visual snow: A thalamocortical dysrhythmia of the visual pathway? *Journal of Clinical Neuroscience*. 2016; 28:123-127. <https://www.ncbi.nlm.nih.gov/pubmed/26791474> <https://www.dhamma.org/en/index>
- 4 <https://www.thegreatcourses.com/courses/the-positive-mind-mindfulness-and-the-science-of-happiness.html>

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May is Better Hearing and Speech Month

Communication: The Key to Connection

NIH National Institute on Deafness and Other Communication Disorders

Information provided by the National Institute on Deafness and Other Communication Disorders (NIDCD), part of the National Institutes of Health.