

Nick Stevens  
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## **Journey to a Diagnosis**

When I was 11 years old, I lived in the dark.

### **How it started**

One summer afternoon, I made a phone call to a friend. I wanted to come over and ride horses one last time before school started up again. I went over early in the morning, and we all saddled up. Not even ten minutes later, my life would change forever.

I was on their youngest horse, Little Red, who was a known scaredy-cat. While riding, one of their dogs jumped out of a nearby creek and startled him into galloping back to the barn. I fell off halfway there. Immediately, there was pain. Arguably the worst I had ever been in before. It felt like my head was imploding. That evening, I went to our tiny farming town's ER.

I was transferred by ambulance to a hospital thirty minutes away, diagnosed with post-concussion syndrome.

### **What it felt like to have a leak**

When I was awake, it was like I wasn't really there. If you've ever seen Jordan Peele's film "Get Out," this will be familiar to you, but having a CSF leak is very much like the sunken place. It's like you're at the bottom of a pool, able to look up at the images happening around you, albeit refracted. At times, you can struggle to the surface, for air, for a few words, before you sink back down, too exhausted to stay afloat.

The following six months are a blur. I was allowed one hour of activity a day. At 11 years old, it felt like an excruciating punishment, being forced to lie in the dark with no physical interaction, no lights, no sounds, no anything.

## **The Twilight**

Just before the accident, I had been playing “The Legend of Zelda: Twilight Princess.” Because of this, I was able to escape, in a way. In this game, you play as the hero, Link, who traverses his world, the world of light, and the twilight realm. Laying flat, I constantly imagined this as my own scenario. I was destined to also traverse the light and the twilight.

As time went on, my daily activity time increased. It took almost a year to go back to normal activities, although I have never been the same since.

I finished middle school and started high school, exhausted and bee-lining for my bed at the end of every day. I was in incredible chronic spine pain, due to worsening scoliosis. I was going to need spinal fusion surgery.

I was now 14, and my spine was slowly crushing me to death. I was terrified for this surgery. In the worst case scenario, I could possibly become paralyzed because of the work so close to my spinal cord.

Before the surgery, I attended a bible study, in which I asked for prayers for a safe surgery. In response, I received an "exorcism." According to this pastor,

there was a demon in my spine. Also, if she was able to expel it, I would no longer need surgery. After all the yelling and hands placed on me, I rode home, quiet, now questioning if I was wrong or evil for having the health problems I did.

Late October, I finally went for surgery. It was supposed to be a long procedure with about a two-day recovery inpatient. Instead, I awoke from anesthesia to a horrifying, familiar nightmare. They stood me up quickly once I got to my room, immediately sending me back to the world-altering pain I had experienced four years prior.

I was 15 years old when I was sent back to the twilight. The surgeon and nurses were upset with me. I wasn't “trying hard enough” to improve. I was “too lazy” to get up and walk.

## **Slowly, a way forward**

It was senior year when I finally heard the term CSF leak for the first time. The next year I was diagnosed with POTS, Postural Orthostatic Tachycardia Syndrome, and Hypermobility Ehlers Danlos Syndrome. It was then that I finally received my referral

to the CSF leak clinic. I did the 48-hour flat test and was given an appointment for about six months later.

The first step was a bilateral DSM. They did not find the leak, but told me of a horribly placed screw from my surgery. When I went back to my specialist, he offered a blood patch as soon as possible. I took the appointment without hesitation, and for the first time in about ten years, I had hope.

## **Patching, and relief**

My first epidural blood patch went very well. My brain felt clear. I had my first moment of actually no pain in almost a decade. About six weeks later, my first patch failed. However, it had given me a taste of what my life could be like. I received a second patch soon after this, although it did not improve my condition as much.

As of filming this, I am about to receive my third patch. I just turned 21 two days ago and I finally have a plan to get out of the twilight. In my taste of upright life, I began my hobby of live action role play, or LARP. I've made a wonderful community of friends there, the closest of which actually learned about CSF leaks to help me.

I spend a bit of time at LARP laying down, but otherwise I'm doing fun things like archery. As I'm filming this, I have two weeks until my third patch. And... Yeah, I hope that the next time you see me in this, I'm doing well.

## **Epilogue**

Hi! This is one week exactly after my third blood patch, and I have a rebound headache, but otherwise I'm doing very good, as far as everything goes. I'm hoping that third time's the charm. There were certain things that were more interesting about this time, just the timing of everything.

It was my patch, and then Friday the 13th, and then the eclipse, which I hope, personally, is good timing for it all, and means that this patch is going to be the one that works. Cross your fingers for me. But yeah, I, I hope you enjoyed listening to my story. I hope it helps people. It has been hard to tell, but that's part of the process of healing.

And yeah, let's, let's go over everything. So, it wasn't a post-concussion syndrome. It was not a demon in my spine. That one's the most bizarre, I think. It was not just, you know, POTS, Chronic Fatigue Syndrome. Although, maybe I have those. It's unsure. And it wasn't because I was lazy and didn't want to get better.

I have a CSF leak. And it's taken about ten years to know that.