

Josh Johnston – interview

My name is Josh Johnston. I'm a forest fire research scientist, leading things around satellite development. And I'm a father of two. And I guess I'm 38 years old. I've had trigeminal neuralgia for about 18 years now.

Before that I was just your average sort of wildland firefighter, and, you know, university student in the offseason and all that. And yeah, to be perfectly honest with you, one day I was walking home from school was in February in Elliot Lake, actually. And I just dropped to the ground right there on the sidewalk. I thought I had been shot in the face, to be honest with you. There was no bang, but I went down hard, didn't know what was happening, just this unbelievable pain in my face. And as a point of strange coincidence, the local hospital happened to be right across the street from the school. So I made my way directly over there, it wasn't even one of those things where it's like, I'll go home and see how I'm doing later kind of thing. It was like, I need to get into the ER instantly and it just happened to be right in front of me. And it didn't take them long to figure out what was going on. And frankly, life's never been the same ever since.

With this sort of condition, there's a lot of different variations of the pain. On a 24/7 sort of basis, there's always this burning sensation. Sometimes it's almost like a grinding feeling that covers just generally the bulk of the left side of my face. But there's also these triggered, what I call, like, attacks where it's a very vivid shock sensation. Sometimes it's localized to a single point, sometimes it'll crackle across the surface. But what it really is, is the nerve itself is sending out the strongest pain it can and it can be extremely disorienting. It can quite literally drop you to the ground. For people to relate to it, it's nerve pain, right? If you've ever broken a tooth and had the nerve exposed, or you know, not quite got the right freezing when you're getting a filling fixed, or something like that. It's a very similar sort of thing. It's so sharp and it's so potent at times, it's hard to even understand what's going on. And I've noticed that over the years, that sometimes I don't even believe that it is a real sensation. Especially once it's gone. Like, the moment it stops, you just don't believe that it could have ever been as bad as it actually was, until it comes back again. And then your memory is abruptly refreshed.

I genuinely, at the time, in that instant, I was worried that like a stray bullet had hit me in the face or quite literally, like, a live wire. And I mean, it didn't take long for me to realize I wasn't bleeding, there was nothing physically, outwardly wrong. The only thing I knew in that moment, was that I was convinced that I was about to die. And I think, you know, as somebody who previously made a living jumping out of helicopters and, you know, working in some pretty rough work, I genuinely mean that statement. And to this date, no matter how many years it's gone on, when those intense shocks hit, in that instant, it's very difficult to convince myself I'm not actually about to die.

But the fortunate thing was, like, once sensibility returned and I was at the ER, and, you know, for the most part, you're experiencing fear. At that point, you have no idea what happened, you have no idea if it's gonna happen in a couple of seconds, or why it happens. I did start to remember that my father had trigeminal neuralgia, and much more briefly, like, he had it for about six to eight months one winter, when I was younger and then it basically kind of disappeared. And so I started to think, Oh, well, maybe this is that thing that my father was dealing with. And, and it was kind of interesting, kind of realizing

that to myself, while I was sitting there in the ER, and at the same time, having the doctor come in and say, you know, there's this condition, or like, well, great minds think alike, I guess.

One of the greatest assets I've ever had was the fact that my father has felt it. And so, I knew one other person who knew what it felt like. Because to be honest with you, after years and years and years of this, it's really a mental game, convincing yourself everyday that it is a reality and that, you know, this isn't you just being crazy or something. That can be really hard and I can't imagine what it would be like if you didn't know anybody who could relate to you. And so I've always been very fortunate that my father could understand and we've had very different journeys with this. But he knows. I don't even have to say it, you know?

It was a difficult time for me. I did not have a family doctor for a period of almost nine years and it's not unheard of in the north, right? And so, I primarily had to go to walk in clinics to get anything; there was no way to see a neurologist, whatsoever. Eventually, I heard a rumor of a self-referring clinic in Toronto where you could go there and they would basically triage you right through to see a specialist, internally and then from there, take next steps. And so my folks drove me down. And that first morning when I showed up there, I saw a neurologist immediately. And by the afternoon, I saw a neurosurgeon to have microvascular decompression (MVD) assessed, when they put some little pillows in to lift a blood vessel off the nerve in my brain. And it worked.

The MVD was quite effective in removing the major frequency of shocks, like we're talking 500+ of those attack moments, per day. It cut the number of them dramatically. But after about nine months, the pain started to reemerge. And a couple years later, we went back and redid the MVD. But after that, that burning pain continued to get worse, the numbness and the whole left side of my face got quite a bit worse. And I think it was almost 10 years before I went back and started looking for the potential to do something else. I had done well, like, the MVD got me to a place where I was able to take on a whole new career, I was able to do a PhD start to finish, which is no small feat for anybody, but definitely not something that I saw in the cards, you know, back when I was laying on the sidewalk in Elliot Lake, right? So when I got to this stage, the load, the amount of pain that I was in, my wife basically put a line in the sand and said, 'Look, you're not as Okay as you think you are.' And I always trust her, because frankly, she is always right.

Initially a neurologist here in Sault Ste. Marie had referred me down to Krembil for a Rhizotomy, sort of an intervention to sever the nerve. And Dr. Hodaie, it was very interesting the way she assessed my situation. I guess there was something about the nature of the pain that indicated that part of it was connected to the nerve damage. And so she figured that if they actually severed the nerve, it might actually get worse. Or at least it wasn't the optimal solution. And so she proposed this idea of, we could potentially put in nerve stimulators to kind of override the signal the nerve was giving, so confuse it, and instead of letting it just do what it wants to do, which is make me pay, we can give me a remote that would allow me to make the nerve feel what I want it to feel. And it'll never feel normal, right. But I can control it to a point now, where it's like a shimmering feeling for the most part. And, again, I'm not cured, right? I mean, I'm banged up proper here, but I have the ability to control it, I'm not at the mercy of it. And I would say that, you know, even a few years on, I'm still managing probably 70, 80% of the pain

just with this remote control device. And I've never had any sort of treatment or surgical intervention provide relief for this long before. So it's pretty incredible.

It looks like a super old Nokia phone, actually. And it's weird because I like, pull it out. And I'm like, adjusting it. And I can see all these, like, the older guys are looking at me, and they're like, he's got a cool phone. And the younger ones are like, how does he still have network access on that thing? But they know what it is. Yeah, there's a couple of different programs that we have in there. There's a baseline one, which the technicians at the hospital set up for me. And I use that almost always, like basically, when I wake up in the morning, I turn it on at a very low level, not like the instant I wake up, but you know, within about two hours of waking up. I can feel the pain starting to sort of creep in on me. And I mitigate it right then and there with a very low amount of signal from this thing. And then as the day goes on, you know, sometimes I can make it through almost the whole day and leave it at the low setting. But I have a normal rhythm to life, where at the end of the day is always going to be rough. And you know, as that afternoon/evening comes in, I'm just slowly turning it up a little bit. And on occasion, you know, I have a separate program where I can tweak the frequency of the electrical stimulation so I can make it vibrate at a different speed, so to speak, and change the width of the pulses and stuff. If that sounds like Greek to you, it does to me too, but I understand it better because I can feel it in my face as I'm pushing buttons.

And yeah, I mean, for the most part, it it's incredibly effective. I mean, everything has limitations in this world, right? And the way that trigeminal neuralgia works or the way that the nerve works, is that, it's kind of like from the bottom of your jaw all the way up to the top of your head. And so when we talked about this with Dr. Hodaie, the real worst of it for me is kind of like from your cheek bone down to your lower jaw. And so the wires are in there, and that's where this is controlling. But any pain that I have above that in my forehead or in my eye, that's outside the coverage zone. So I still feel that and the same thing with my lips, right out to the tip of the center of your lips. Sometimes it'll creep over there.

We had progressed to a point where I wasn't driving, ever. I wasn't ever being left alone with my young kids at the time. Because, well, for a lot of reasons, right? I wasn't able to focus, I wasn't able to think clearly and you don't want your kids seeing you falling down like that, right? It scares the bejesus out of them. And for my youngest son, like, after he was born, and it was within a year or two of him being born that I would only hold him, if I was sitting down. And my wife would like, put him on my lap kind of thing. There was no way that I'd ever be picking him up standing there. I couldn't do that. I can do that now. And I don't know how to explain to folks how much that means.

Outwardly, there's literally no trace that anything's wrong with you. Everyone sees you and you seem normal. And you're enduring an unimaginable hell right in front of them, and they can't tell. And your kids are sitting there wanting to play with you. And your kids, you know, a two year-old wants to be held. And you can't do it. And you're in your 30s. Right? Like, it's, it's not cool. So, I can do that now.

No, I still don't drive and that's fair ball. Frankly, I was never that good at it. But, you know, I can pick up my kids. I mean, barely, because they're gigantic at this point. Like my five year-old is like, over 70 pounds. He's a big boy. He's gonna be carrying me soon is what's gonna be happening! But, you know, I can do that. And oftentimes, I can just sit and play games with them. Or, you know, if my wife needs to

go out to the grocery store or something, like we don't all have to pile into the car just so that she can babysit myself alongside the others. And they're small victories I think.

It was almost exactly like waking up out of a coma. This was 15 years of completely lost time in a lot of ways. But I, very clearly, was still doing things, because I woke up and I've got a career and I've got a family and it's amazing. The kids love it. We've had to explain in detail to the junior kindergarten teachers why my son insists that I'm a cyborg. And robot Daddy was his was his superhero.

Another weird thing that happened was, in the wake of this change and the surgery, I slowly started to feel less burden. And I don't know how to explain that, other than to say, it's probably that my heart rate, my blood pressure dropped off a cliff when I was finally out of all that pain. And so, whereas before I was having trouble walking upstairs, I was able to start doing things like riding my bike again. And, you know, initially around the block, and then five kilometers, and then 10, and then 100, then 200. And I think when I got to 230 kilometers in a day, I started realizing that, you know, there's possibly no real limit to this. And in the end, I opted to put it to some good and I did a fundraising ride to support Dr. Hodaie's work. And it was a lot of fun. We biked about 4000 kilometers for that fundraiser. But I haven't stopped since, to be honest with you, I ended up biking almost 10,000 kilometers last year and I'm way deep into it, this year too. But, kind of like, I said, there's nothing physically wrong with my body. But the load that pain puts on you, it wears you down and it leaves you with very little left. So just removing the sensation of the pain, it changed everything so much. Like, I almost immediately had to come off of my blood pressure pills, because, you know, they were making my blood pressure too low, and my level of fitness just shot up like a rock. I used to just think that was out of the question. So hey, you don't ask questions. You just roll with it!

The reason I want to support Dr. Hodaie and the reason I want to talk with folks here is twofold. One, for anyone who doesn't have a dad like mine or anyone out there who has this pain and doesn't know anyone else who has it, you're not alone. All right, you're not alone. And I know it's rare. And you probably aren't going to bump into a lot of folks on the street like this. But, it's not just rare. It's also extreme. And when you have that trifecta, kind of what you end up with is, there are brilliant researchers out there trying to solve it. And what Dr. Hodaie gave me is hope.