

## Adriana Salazar – Bonus Episode Transcript

Adriana Salazar 00:19

[gentle electronic music] My name is Adriana. I just turned 40 years old. Married, one kid - only child. She is going to be five next month. I was on my honeymoon—I was in Portugal—and I felt a pain on the left-hand side of my face, mostly on my nose, and I was like, "Oh, well, this is weird," but I had just gone to Portugal and I was like, "Maybe something on the flight. Who knows?" I chalked it up to I was travelling. And then, the pain went away, so I was like, "Okay, well, it was nothing."

And then I became pregnant in 2019, and I felt the pain again, and I was like, "Okay, well, this is weird." So, I went to the doctor and they said, "Well, because you're pregnant, we cannot do any exams." And then, they said, "Pregnancy changes the body, so this is all pregnancy related. You will see. It will go away," and I was like, "Okay."

Meanwhile, I couldn't eat some days or I couldn't smile some days and I'm like, "Man, this baby is kicking my bum," but I chalk it up to pregnancy, right? It was pregnancy related, and that was the end of it. Meanwhile, I also saw a dentist who referred me to a specialist of pain and he said, "I can do none of the exams because you're pregnant. Once you're not pregnant., come back and we will do more exams." I was like, "Okay."

I had my baby. The pain went away, and I was like, "Oh, look at that. Definitely was the pregnancy. Nothing to worry about." About six months after I delivered my baby, the pain came again, and now it was stronger – stronger than the first time, stronger than the second time. And now, it is just a shock of pain on my face, especially on the top side of my left, going to the eye. And, ever since then, I just had the pain. It will come, give me the shock-like pain, and then go away. And, it just progressed. The intensity progressed and the duration of it progressed, and everything just started to escalate.

So, I was, at that point, in contact with a neurologist. She then asked me to do an MRI and that was when it was determined that I had trigeminal neuralgia and that it was very clear that I had a vessel affected, that it was a possible compression of the nerve on my left-hand side, but that it was in both sides. So, I have it in both sides, but it was more prominent on the left side, and this is the side that was hurting. And, ever since then, I started my journey of medications and pain until I had the surgery. [music ends]

The pain that I felt, I felt like electricity was pulsating inside of my face, like a very electric shock, [electricity buzzes] and it would go from the top of my mouth all the way to the bottom of my eye, to the point that my eye would shake, and you could see it moving. [electricity buzzing crescendos then stops] I delivered my baby naturally, and I tell my husband, "I'd rather do that with triplets and I'll be fine if I didn't have to experience this pain again."

[pulsating electronic music] It's a pain that is so hard that it brought me to my knees a few times and you just cry because there is nothing else you can do. You hold your face and your face is pulsating, and you just feel this electricity and it's just lightning bolts inside of your face and you can't control them. It's agonizing, it's debilitating, and you feel so helpless and so useless that it just brings you so down. You

turn into a bowl of mush at that point. I have never experienced greater pain in my life than what this condition has given me. [music continues then fades out]

I was very excited to go home, to go back to Colombia and it was the first time my daughter was going to be spending Halloween with the grandparents and we had this trip planned and it was going to be a fantastic couple of weeks. And, we got to Colombia and everything is going okay, and then my daughter got extremely sick. [bubbly electronic music] For most of the duration of her trip, we were at the hospital and she's going through a lot of exams and a lot of tests and blood being drawn, and nobody had any idea what she had. Nobody could figure it out.

And, it was the day to come back to Canada and, magically, that day, she woke up and she was back to herself and we're like, "Okay, let's go home." So, we are home and we have different access to a different health care—not to say that Columbia health care was bad—but different healthcare, different people that may have no different diseases. So, we make it to Canada and she's doing okay. But then, her fever came back and at around 3 o'clock in the morning, she woke up and she just screamed that her leg and she couldn't move and her leg hurt. So, we rushed to the ER and they redid every single test that they had done already in Colombia, and at that moment, they told us, "Well, she has had a fever now for nine days. This will be the 10th day, and with [Kawasaki 00:06:01], on the 10th day, then there is a possibility that her heart is going to be compromised. We have to give her some blood to treat the disease.

And, at that point, I'm like, "What? What is happening?" But, of course, like, her heart is compromised, so let's give the blood. And then, she gets put. Into a room and they're just about to start that, and then a doctor comes in and says, "Hey, guys, I'm usually not in on the weekends and when I get called, it is because there is something really wrong." We're like, "Oh, fantastic. Why are you here?" He's like, "Well, your daughter seems to be also having a hip infection, and if we do not operate now, by the time she's five, she's going to have the hips of an 80-year-old. And, we're like, "What is happening?"

So, meanwhile, they started the stuff for Kawasaki's, so she's on that. We finish the procedure which takes a few hours, and then she's just rushed onto emergency surgery because she may have a hip infection. They couldn't really know because they didn't have time to do the exams, so she was just rushed to do that, and it was just a lot of hours of crying at the hospital in the praying room and worrying and pacing back and forth.

Throughout this time, I'm okay. Like, I'm not feeling other than the regular pain that is being managed with my medication, so I'm not really paying attention to anything. I'm just worried about her. She comes out of surgery. Surgery is a success. She can walk again. Her fever comes down. So, we're like, "Oh, my God." Like, "Thank you, God. Thank you, God." [music fades out]

We bring her home few days later, and the moment I got home, I got hit. [collision thumps] It was like a slap on my face, and it was just a wave of pain, so unbearable, [electricity crackles intensely] on my knees on the floor, crying, holding my head, and walking back and forth because I couldn't deal with that anymore. My husband, oh my God, he was such a trooper throughout all of this. He's bringing me ice; he's bringing anything that he can think of.

[bubbly electronic music] Right after that, he managed to get a hold of someone's email. He ended up emailing Dr Hodaie's office and he said, "Honey, I emailed him. I cannot bear to look at you anymore." Luckily—and God is great—they answered, and by December 7th, I was meeting with Dr Hodaie.

After that, I am told that I have to get an MRI and then I have to come back to do all the other exams. We booked the MRI for, like, six months in the future, so I was like, "Oh, my goodness." So, I'm freaking out because I couldn't deal with the pain. Honestly, it was one of the lowest points of my life and I'm not very happy or it doesn't please me to say that, but I did ask my husband at that time to let me go. I said, "If my life is like this for the rest of it, please let me go," because I couldn't deal with it. [emotionally] And, it's now, looking back at it, it's like, "Why was I so weak?" You know? But you realize it's just the pain talking for you. It's so painful. It was so painful. [laughs wryly] [music fades out]

[upbeat electronic music] So, the MRI is booked months in advance and I was like, "How am I going to live for the next four or five months until I get the MRI?" and luckily, somebody cancelled and I got to Toronto in a week or so after, and I did the MRI. They asked me if I could help with the extended MRI. I never had an MRI done before, so I had no idea what to expect. I never had any surgeries done, so I'm freaking out from all sides. I got the MRI done. By January 8th, that was my surgery, so it was a very short turn around from when I met her to getting my exams done to getting the MRI done, to having surgery, and I couldn't be happier because it just happened so fast, there was not enough time to process. It was just like, "Oh. It's today." They called me, like, the day before. "You have to come tomorrow," and I'm like, "I'll be there." Like, they asked us, like, "Are you okay?" and I'm like, "Yes, yes. Like, let's get it done."

So it's a little emotions in one because you don't know what to expect from a surgery and a surgery of this caliber, at that, but at the same time, you're excited for the possibility of no pain, because you don't know if you're going to be one of the lucky ones that has no pain, or if you're going to be one of the unlucky ones that you have to get it done again. So, there is definitely a lot of emotions at that point. [music fades out]

[rhythmic electronic music] I had the MVD, which is the microvascular decompression. So, basically, they open my skull, go in, fix it, come out. It sounds very simple. [chuckling] I'm sure it's extremely complicated and lots of years of experience to do that. I do not know a whole lot about the surgery other than it is just a surgical procedure to relieve the symptoms of pain due to a nerve being pinched by an artery or a vein. So, that's what I had done.

I am doing so much better. Honestly, I have my life back. I can eat. I can smile, I can laugh, I can kiss my daughter. I'm so grateful. The first few days after the surgery are rough, as any surgery, and they're hard because it's a lot of pain on the back of your head. It's a lot of pain, overall. You don't want to eat, you don't want to do anything. But in the long run I am better. I still experience some pain every now and then, but it's not that pain. It's more of a bruised type of pain. So, the recovery, I think it is still ongoing. My headaches have improved. I was getting a lot of migraines, so that has definitely improved, as well. [music fades out]

[gentle electronic music] The medicine that I was on, it was called carbamazepine, so it's an anti-seizure medicine, so you cannot stop that medicine on the spot; you have to go down. But, my neurologist didn't want me to stop the medicine until three months after the surgery. She said, "If you were to start reducing them right after, if you came back, then you have to go up on the medicine again, so we're going to keep you for three months. After three months, we're going to meet and see where we are and then start reducing them."

So, I have just been medicine-free only for a couple of months now. It was last month that I went fully off. I haven't taken any carbamazepine or any gabapentin or anything for the pain. [crossfades to upbeat electronic music] I am so happy not to have the electric-shock-like pain from trigeminal neuralgia. That being said, the first month or so, there is definitely incision pain. There is definitely headaches and migraines that come along with it. I was busy, but I was also on a very high dose of carbamazepine. It was the highest I've ever been, so I didn't know if I was dizzy because of the surgery or because of the carbamazepine because the time frame, it was so short in between when I increased my carbamazepine to this. But then, I was like, "Okay, I increased it to the max and I was still feeling it." So, at this point, I wasn't sure the carbamazepine was even doing anything, so I reduced that. I was able to reduce it to 900. I was still having the same amount of pain.

I was like, "If I'm going to go through surgery and then have to reduce it, I want to start at a lower point if I can manage it. The difference between the 900 and the higher dose that I was taking, I will say it was none, and that's why I reduced it to the 900 with the doctor's blessing. But, it was still excruciating pain all the way until surgery. When they asked me if I wanted to be part of the study, I'm like, "Sign me up. Anything to help anybody," you know, just because it's so hard. And, it gets misdiagnosed so often because it's like, "Oh, it's your teeth that hurt. Go to the dentist." [chuckles] I'm so happy somebody's researching this. [music fades out]

[bubbly electronic music] To the team at Western Hospital, honestly, I am so grateful for everyone. My nurses were fantastic. They took so good care of me. I wish I would have taken more time to learn more of their names, but it's such a fast procedure that you don't have the time to ask them. But, even the gentleman that rolled me into the operating room, he was trying to bring my nerves down because he knew I was nervous. Everybody knew it. You could see it on my face. I was freaking out, and the anesthesiologist, she was fantastic. It ended up being a different person than the one I had met before, so I was really like, "Oh, no. Changes." But, she was fantastic. She was so great to me and Dr Hodaie, I honestly owe her so much of my life now.

One of the hardest things I think, for me, was going day by day, not being able to kiss my daughter goodnight or good morning, or just even play with her, because if she would grab my face, the pain was so hard, and to be able now to let her touch me or be able to kiss her goodnight, it has been the world. So, I am so thankful for everybody. Everybody took fantastic care of me and to Dr Hodaie, honestly, she was sent by God to me, so thank you. [music fades out]