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Bridging the Gap conference  
November 11, 2023

## **Patient Talk: The Surgical Experience**

My name is Claudia Perez Sandhu and I'm a physician, family medicine physician. In 2020, I was at work listening to a meeting and I had a cough, which led to a very funny sensation in my brain, almost, I described to people, like a firecracker, which wasn't intense. But then that developed into a headache which continued to progress on the same day to the point that by that evening I was in excruciating pain, a headache that I have never felt before.

And finally, my husband suggested I should lie down and see if sleeping it off will help. And to my surprise, when I went to lie down, the symptoms resolved within a few seconds. And I thought that was a fluke, so I sat up, and within seconds, again, I started feeling that horrible, excruciating headache.

So, that same evening, I called our neurologist on call. And within a few minutes of listening, she goes, you know what, I think you're having a low-pressure CSF headache. She recognized it right away. I had no idea what it was, to be honest with you. I've been practicing since 2008 and I have never heard of that. I just knew that a positional headache was not a good sign.

I got on Google. I got on Up to Date. I started looking at research online and educate myself because, as I mentioned before, I have never heard of this diagnosis. I knew it could happen after a lumbar puncture or epidural, um, you know, and it's usually immediately recognized. But I never knew this could happen spontaneously.

So the diagnosis was suspected. It was not confirmed. When I went to the emergency room, they ordered imaging for me, and they spoke with a neurologist on call who suggested they should do a blood patch. Um, the anesthesiologist on call had never heard of it and felt very uncomfortable doing a blind patch, not knowing where this potential leak was. I appreciated the honesty from the doctors and I chose to be discharged since there was nothing they could do. And a few days later, the neurologist that I had talked to, um, had done some research and she found an interventional radiologist within our health network that was pretty familiarized with spinal leaks.

His team looked at the images and apparently they could see that somewhere between T6 and T7 there was a suspicious area that indicated a possible leak. So I want to say within probably two weeks, I was going through a CT myelogram, um,

and had my first patch. And unfortunately, days went by and it did not make any difference in my symptoms.

I kept communicating with a specialist and about a month after, they scheduled me for a second patch. And this patch gave me some partial relief. I was able to be upright for longer periods of time without significant headache. I still had a degree of headache and I would feel extremely out of it. Like, like I was like, my brain was in a fog. I just felt like it was just, it was just being in a different body. Let's put it that way. I just felt off.

After three months of the last patch, this interventional radiologist suggested a different approach because my leak was on the front of the spine. So I chose to go for it and we did a, it was just fibrin at this time. Unfortunately I developed an anaphylactic reaction to it. So it got to the point that they said, well, next step is surgery. So I met with a surgeon and he reviewed my case and I felt a little bit of indifference about what to do. He was more like, sure we can do it, but you know, if you're 80 percent better, you've got to take into account the risk of surgeries. And do you want to risk it for just getting that 20 percent more? So, I ended up asking another surgeon with a lot of experience, on the side, I emailed him. And he told me, "You need to go through surgery. You need to have surgery done. I think that will be the ultimate definitive treatment for your case at this point."

So the surgery that I had was a laminectomy with a dural repair. They had to cut through an area of my vertebra and remove some of those pieces of bone in order to be able to pull the spinal cord and get to the area of the dura where the leak was. So, knowing what it involves and being in the medical field, I was extremely fearful of a complication because, unfortunately, that's something that you have to assume. It's a risky surgery.

So that surgery, uh, first of all was very challenging. I had to request an out of network referral, which was a very long journey. Thankfully I was able to get it. So I had to travel outside of my home to go and get the surgery, and be, you know, in a hotel for the first few days after recovering.

I have two kids. I couldn't stay there forever, so I have to come back home. And it was so scary, uh, traveling back after a few days of surgery. Um, every little bump, every little movement, I was fearful that that could cause some damage. Um, so recovery from surgery, away from the medical team that had performed the surgery, was like being on my own.

So my first, um, sense that I was getting better is that I was not getting the headaches when I was standing up. So I was in pain in my spine and I was having a lot of those post surgical symptoms, but the headache was not there. So every day I prayed, you know, like it will continue that way. So it was more at that point just being watchful of those symptoms that I used to have pre-surgery, leak-related. But then I was left with the other symptoms that I knew that were going to come, but I just didn't realize how severe they could be. The pain was pretty intense. Just doing

my daily activities like taking a shower or sitting up for prolonged periods of time, it was, it was quite challenging. Um, and having two kids and having a dog, you know. Trying to be there for them. That was a little difficult too, but thankfully my whole family was pretty understanding and even my dog behaved so well during those days. So that helped.

So I was scheduled to be out of work for, I believe, two months after the surgery. And even though I was feeling significantly better after two months and being able to be upright, the pain was still pretty intense and debilitating in my back. I didn't think I was going to be able to go back to work and do the full eight to 10 hours.

And, you know, sometimes depending on what I'm doing, I have to be able to do certain lifting and movement, if I have to do, like, a knee exam, for example, so that was a little bit of my concern. So I ended up, me, asking for more time off.

You know, nobody checked on me to say, Hey, how do you feel after two months? Should we send you back to work? Or should, what do you think we should be doing at this point? I was the one reaching out and saying, I don't think I'm going to be able to. Nobody asked me, it's like. What is your work like? What do you have to do at work? Do you think you can perform your work? Never.

Now that I am two and a half years after my surgery, I want to say I still feel like a 10 percent of pain in my back and my neck. But it's obviously much better, but it takes a while. It takes a while to feel that. Headache? So far, so good.

I think I'm at a new normal. I think I have to like, learn like, okay, this was a risk that I knew could happen. Uh, you can, you can end up with chronic pain after your spine surgery. Um, I didn't know about this post-laminectomy pain syndrome that can be seen. And I think that's what I was going through. And I think I still have some degree of it, but I have learned to accept that in exchange for not having those debilitating headaches.

In the back of my head it's like, this could come back any time. I just try to take it one day at a time and not constantly think about it. Um, you know, every time now, if I do get a mild headache and I verbalize that and say it, everybody's like, is it the leak headache? It's like, no, no, no, no, no, it's just, it's just a headache. I know, I know what it felt like.

I think the take-away for me was that I would recommend having some support network, not just with family, but someone that has gone through it, uh, someone that can just at least listen to you and say, yes, this is normal. Yes. What you're going through, it is real.