

## **Patient Voices: The Truth About Epidural Blood Patches**

Bridging the Gap conference

November 11, 2023

**Theresa:** So, um, blood patches are really a crazy thing. They don't really know how it works, but it works.

**Lillie:** It was, I would say it was painful.

**Michal:** I think the experience was not that bad for me.

**Theresa:** My bedside blood patch was actually the most traumatizing experience in my life.

**Aubrey:** I just felt so fantastic after my blood patch and was so happy that I went out to celebrate and got Mexican food pretty much as soon as I was discharged from the hospital.

**Rita:** My blood patches, I think, were a fairly positive experience.

**Mike:** I probably have a little bit of PTSD from all of the patches that I had that worked for a short period of time.

**Lillie:** So the, my first blood patch, so I, because I'd waited so long, it had been going on for a year that I'd been having this low pressure pain. So when I finally got told, yeah, you need a blood patch, I was just so desperate to have it that I wasn't nervous or anything. Yeah, I probably, I went in a bit, maybe naive, because I was just like, yeah, I just want it and it's going to make me better. So I'd obviously, I'd watched sort of YouTube videos of other people's experience and it did actually look a bit grim. I was just thinking like, no, it's going to be fine. It's going to be fine. Um, the actual procedure itself was awful. It was, it was really quite traumatic. Um, I had local anesthetic. So I was awake and I feel like local anesthetic for most normal procedures is fine, but anything to do with your spine, you can't really, you still feel all the nerves shooting around and you can tell that someone is so deep in your spine because it's just the most unnatural sensation ever.

**Michal:** Um, the blood patch, I think the experience was not that bad for me. I mean I did it without any sedation or anything. It was pretty okay. I mean, it's, you know, a little bit uncomfortable, I might say, but other than that it was okay. I didn't feel like it was, you know, major stress for me or a major, um, pain issue. I did need to rest after that because there was some lower back pain, but it felt like, you know, it's normal to have it after, after such a procedure.

**Theresa:** A lot of my doctors have dismissed me after the second patch did not work. Like, oh, well, that can't be possible. People usually heal after two patches. Yeah, usually. There's a, there's a percentage of people who really don't and they struggle.

**Rita:** When they didn't work, or partially worked, or worked temporarily, you definitely, and they say that it failed, yeah, you definitely feel like you did something to not make it stick or make it work. And I think that's what's really challenging, is that there's not a lot of good concrete evidence about where to put the patch when you don't know where the leak is, how much blood volume to put in, what the patient should do post patch, and for how long.

**Mike:** So the first one that I had was instant relief for me. I woke up and my eyesight was better, my balance was better, my head pain was gone. And that was really the amazing part. Because what I think a lot of people, doctors included, don't understand is that the amount of pain that CSF patients endure through this process is... it's unprecedented. It's unbelievable. So, when you wake up without that for the first time in months, you know. And I told my doctor and I said, My head pain's gone. And he could just tell, and my body just felt light, and the pain wasn't there, and unfortunately it didn't last. Um, and most of my patches, unfortunately, didn't last. So, I probably have a little bit of PTSD from all of the patches that I had that worked for a short period of time, and it gives you your life back for a small period. You can eat dinner with your family, you can sit up, you can watch TV, you can eat with your head up, I mean, that's something we take for granted. And then it goes away. So, unfortunately.

**Emma:** For the procedure, I was in an operating room and they had me crouched over a pillow. They froze the area where the epidural needle was going into and that was the worst part. That was the only pain I had felt. And then they withdrew blood from my arm and began injecting that into my spine. I had to notify them when, um, the pressure became too much in my spine, and then they would stop. As they were injecting the blood I felt a little bit of tingling in my leg. But that went away. And after the procedure, I just had to lay down for several hours. In another experience with a blood patch, they had difficulties locating the epidural space in my spine so that was a bit painful because they continuously were pulling the needle in and out to try to find that space. And from that experience as well, as they were injecting the blood, I immediately felt a headache alongside, um, some nausea and, uh, a little bit of faint. Um, but other than that, it was okay.

**Anna:** It was a lot easier of a procedure than I thought it would be, they had a really great team at the pain management center that I went to. I had my life back, it had worked. I couldn't believe it, I couldn't believe—I didn't believe it would stay, um, because it was too good to be true, um, and then about five days later, my symptoms came back. I needed a second one, and I went through the same routine with the team at the Pain Management Center, and after the second blood patch, I

have been symptom free for, um, maybe six months now, and I hope to stay that way.

**Aubrey:** To me, my blood patch was a life-changing procedure. It gave my life back for about five years. In my case, I had a leak that was presumed but not located just based on my symptoms. My doctor referred me for a non-targeted blood patch in the lumbar area and told me not to get my hopes up, you know, that the odds were that this wouldn't work the first time, but that this was a procedure that we could try, um, to hopefully give me some relief. So, I had this procedure done, I was put under, pain was really not bad from the procedure at all. Um, and when I woke up, I just remember crying tears of joy, because instantly like a light switch had been flipped, my head pain was completely gone. It was like magic, that was how crazy it was, not even the slightest bit of it remained. So the hospital that I did it at, um, is not like a major hospital or university hospital or anything. So, um, I don't think they were up on the latest restrictions after blood patches and all that. So I wasn't really sent home with the typical no bending, lifting, or twisting, um, kind of instructions. So I didn't know that I was supposed to be careful after and I just felt so fantastic after my blood patch and was so happy that I went out to celebrate and got Mexican food pretty much as soon as I was discharged from the hospital. So not something I would recommend, but my blood patch did hold for five years. I now have since developed a different type of leak, which can happen, but the blood patch lasted a really long time. I feel like in, in our spaces as patients, you hear about a lot of people whose blood patches don't last for very long. But there are some of us who do get many years of relief after a single blood patch. So um, there's hope too in that, in that way.