

Patient Voices: Post-Patch Care and RIH
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Claudia: So after having my first blood patch, I was given a little handout and I read through it and I was like, okay, yeah, this is what I got. But what am I supposed to do? Am I supposed to lie down flat for 7 hours? 6 hours? 4 hours? Am I supposed to even get up to go to the bathroom? There was nothing. I had to go online and start researching. Like, what do you do after a blood patch or what don't you do after a blood patch? So I learned that, you know, certain amount of rest, no straining, which nobody told me. So unfortunately for patients who suffer from constipation or cough or something in those lines, and they have to do that forceful valsalva or, um, you know, a strenuous cough, that can be, um, actually a little bit of a problem. If somebody is going through a upper respiratory issue or they have chronic cough, they should be given something to suppress the cough. And the opposite, they should ask, uh, do you have constipation? Do you suffer from constipation? They should probably anticipate, um, that that patient should have those treatments in place or those recommendations given. So, no, I was not given a good, clear, and I'm sorry, I don't mean to sound ungrateful to the team that treated me. But, uh, but I, I think that's something that should be incorporated after any blood patch.

Rita: There might be some guidelines, but even with that, I think there's still a lot of gray muddled area. And most people can't be completely supine in bed for 48 to 72 hours. Like, most people cannot follow that, especially if you have young children like I do. So, yeah, it's a little bit disheartening, I guess, to go through multiple blood patches not knowing if they're gonna work. And when they don't work, is that something that I did? Or is it something that... My leak isn't going to be amenable to that treatment. And that's, and that's challenging for sure.

Mike: I've had so many patches that I had to heal from that didn't work, so I didn't really know like if it, you know, do I really not have to sit up or can I really not twist after week two? So every hospital, they all tell you something different, and I think the reality of it is they really don't know what doesn't work. You gotta just be careful. I think, you know, the one doctor will say, well, somebody, you know, coughed and that opened up, but you don't really know what opens up for you to re-leak, but you gotta just really try not to carry stuff. You got to have somebody help you, you know, because you can't do a lot of things you normally do. So you have to, you have to listen, you have to really take care because it is, it's fragile.

Theresa: Recovery-wise, uh, I usually stay flat for an entire week after my patch. No pillow. I do mostly bed rest. I try to be very strict. Um, I equip a reacher grabber. My little reacher grabber stick. And I'll make sure I'm equipped with all my laxatives. Cough drops are really good because sometimes laying down you get a tickle in

your throat. Um, nasal sprays, keeping your nose clear of mucus is one thing. Um, but for the first week it's usually very rough. It's uh, very, you're kind of like feeling out, is this patch going to work?

Lillie: But then I had rebound high pressure, which I think maybe they had told me might happen, but I wasn't, I don't know, I didn't know what to expect. So then suddenly it hurt to be flat, so I was waking up in the morning with this banging headache, and I was so confused. And then once I'd been upright for a while, it went. But then if I was on the sofa or something, it'd come back, and I was thinking, What on earth is going on? And then I realized, oh, it's high pressure. Um, which is really annoying, but it happens.

Rita: That was difficult, just, I think, knowing that it would happen, but not quite knowing what it would be like. Knowing that it might happen, right? Like, not everybody has it, but knowing that it could happen. And, um, but not having any really idea about what that would be like versus, like, kind of an opposite headache. It was much more than that. It felt like anxiety. Like, horrible anxiety when I tried to lay down, which was like, my respite prior. So, like, trying to lay down at night or just waking up in the middle of the night, just being horribly anxious. Plus, just the huge head pressure. Nauseous and dizzy, but like, in an opposite way.

Mike: I felt pain in the front of my head, and it was like somebody was pushing out my forehead, and that was a much different complexion of pain than I had had.

Lillie: For me, it felt like literally someone had just flipped a switch on the low pressure. So, instead of pain being completely alleviated being flat, it was brought on by being flat, which is arguably worse because you can't even like sleep comfortably. Like at least with low pressure you can go to sleep and be flat. Um, but so it was difficult because then you'd have to sleep as propped up as you could be, which you don't get very good sleep. Um, and anytime you want to just like relax, you have to be like super upright, which is uncomfortable.

Claudia: It was more like my, my brain was like too big for my skull. Like it was almost like it was going to explode inside. So I told them what I was feeling and they immediately suspected that I was having a rebound hypertension, intracranial hypertension. So, um, upon discharge, they recommended a diuretic for me to take.

Mike: It's a tough medication. I'm not gonna lie. Um, it's, it dehydrates you severely. It just makes your body really, it's tough. So like I have seltzer, I drink water and I drink seltzer all the time. This tasted like drinking tin. And so it changed the, the taste of a lot of things for sure. And it made my, it made my extremities numb, um, constantly, which was strange.

Lillie: It basically gave me really tingly extremities. It was really bizarre, so my hands and toes felt like, not pins and needles, but kind of, almost like I'd been sat on them for hours, which I hadn't, so it was strange. Um, and you weren't meant to drink

alcohol with them, or you could, but not very much, and it was like, um, the Christmas, New Year period. So that was a bit annoying. Um, so I didn't take, I didn't take it for very long at all because it wasn't very nice. So

Rita: It was, it was just, it just felt like I was quite sick. I felt ill. I'm like, am I allergic to this? I'm like, what's going on? And what was hard is nobody had a good answer as to why I was feeling horrible. The intense symptoms probably lasted for one or two months, but I was able to slowly kind of decrease my dosage, and then I figured out how to control my diet, my activity levels, and just using some other, like, the dandelion tea and like it, you know, all those other kind of natural diuretics and detoxifiers and just to see if that would help, and it, and it did, eventually, and I'm now able to manage, but I still have some symptoms of hypertension at times.