

Patient Voices: What Doctors Should Know  
Bridging the Gap conference  
November 11, 2023

### Amy

By the time we make it to your office, we've been waiting, typically in a state of perpetual agony for many weeks, months, sometimes even years. Our lives, our ambitions, our relationships, all have been held captive by our pain and disability. Yet time marches on and leaves us behind, frozen in that instant that our spinal CSF leaks began.

And so, when we do finally reach your office, we are consumed by desperation and overflowing with hope. Desperation to reclaim the time remaining to us, to not waste more of that precious time waiting. Hope to recover the lives we once lived to rekindle the dreams we once dreamt.

### Aubrey

What I wish that my doctors knew about living with a spinal CSF leak is how much research and advocacy it often takes on the part of patients to reach the correct diagnosis and treatment.

We often have to do a lot of legwork on our own to get to this point and what that looks like on a practical level in our doctor-patient relationships is often myself and other patients will like to ask a lot of questions or understand the reasoning behind certain tests or treatments that are, that are being done.

And we promise that we're not trying to take on the role of being our own doctor or be difficult when we have a lot of questions on that kind of stuff. Ultimately we just want to understand the decisions that are being made with our own care and treatment, and ultimately, at the end of the day, get better.

### Sara

Something that's helpful for providers to know is, along with the crippling pain, nausea, and fatigue, one symptom that was extreme and overlooked was my level of brain fog. It feels like brain fog has become a buzzword these days, but this level of cognitive impairment was so significant, I could not even remember my own phone number when sitting upright.

Coupling that with extreme sensitivity to light and sound made it incredibly hard to relay symptoms and absorb any information given at appointments.

### **Judith**

What I would like the world to know about living with this condition is that it's not just a headache where you pop a few pills and a few painkillers and everything will be fine. It's an assault on your complete central nervous system.

### **Sarah**

One thing I wish doctors knew about spinal leaks is that they are so much more than just a headache. In my case, I feel sick in some ways that are indescribable. I have tinnitus, severe neck pain, constantly dizzy in many ways, zero sense of balance, can't think, a heavy head, spinning vertigo, a pulling down feeling that's so uncomfortable from the minute you're upright, weird vision issues and more. I wish it was just a headache.

### **Mike**

I think one of the other things that the doctors don't really understand is just the quality of life gets so eroded and you get so debilitated and the pain is just, it's the suffering that you go through is, it shouldn't be allowed for a human to deal with it.

Your body just goes through so much torment when you're leaking. It affects your liver, it affects your kidneys, it affects your bladder, it affects your esophagus from throwing up, it affects your eyesight.

I mean, your whole body is just in this onslaught.

### **Pam**

I am a 70-year-old woman who is mostly in bed due to a presumed leak not seen on either a brain MRI or a CT myelogram. My first try at a blood patch was unsuccessful and I can tell you that from the moment I roll over in the morning and stand up to get out of bed, I am in agony. I can barely run a quick errand without causing even more pain, and I'm just barely existing at this point.

### **Shelley**

I do feel at times that I am slowly just disappearing. The days are so long. The physical pain is just so hard at times. And that constant fear and worry creeps in all the time of just how long will this go on for?

### **Sara**

Some patients are sealed and healed very quickly. Others have very slow healing time back to a functionality level. My leak began in early January 2017, and I've had a multidisciplinary team helping me recover full time for the past six years. I'm still doing therapy for the subsequent dysautonomia and deconditioning of the leak.

### **Claudia**

I don't think we should be expecting family physicians to be experts in this field, but to recognize that this disease exists and to put it in your differential diagnosis.

So, obviously postural headaches, but also patients who have had these unusual headaches that are not getting better with anything. I think that needs to be put out there, I don't know how, in the medical boards or just bringing it up more in conferences when they speak about headaches. Because I work with a group of like close to 40 physicians and none of them, none of them had ever heard of this spontaneous leak.

### **Mike**

There's got to be more education, I think, down to the ground level of hospitals because people present and get turned away and they get told they don't have a spinal leak and they probably suffer for a really long time and some of them probably never get fixed.

### **Michal**

I think my main message is, uh, think it up in your differential diagnosis when you have a patient that comes to you and says, "In the morning, I feel great. And in the evening, I don't feel great. And my hearing changes and fluctuates during the day." I think it's a huge, huge sign to clinically think about as a doctor.

There is hope. There is hope in this field. So this is why the awareness is important.

### **Anna F**

My two biggest wishes is that there are more neurosurgeons who are willing to perform exploratory surgery. Because in the cases like mine, in the cases of an epidural and iatrogenic leak, uh, you won't be able, or would very rarely be able to

see it on an MRI or, or even a myelogram. And I also hope that there would be more photon-counting CT scanners available to find evasive fistulas.

### **Shelley**

Spinal fluid leaks are debilitating physically, emotionally, socially. Each day is a struggle to deal with the physical relentless pain as well as the isolation of not being functional.

The reality of what patients are dealing with on a daily basis when they go home is not really being addressed.

It would be wonderful to have someone on the team that is a social worker, an advocate, or a specialized nurse that can address the physical, social, emotional issues of the whole patient.

### **Judith**

I would really love to see three things more acknowledged by the medical establishment. First, leaks aren't always visible on MRI. In fact, a minority of iatrogenic leaks will be visible. Second, that there are certain risk groups that we know about and some that we have to research better, such as being female, people with connective tissue disorders, and maybe ME/CFS and mast cell activation.

And third, the timely treatment will really be an advantage for the patients, so don't send them away and tell them they'll be fine.

### **Mike**

It's very important, I think, for the doctors to really listen to the patients so that they can understand what these symptoms are and when they return and things like that because it's invisible.

### **Sara**

Another area that would be amazing for providers to address is the support person of the patient. Often everything is so patient focused, they get brushed aside when they desperately need to be heard as well.

### Shelley

Being in this space isn't only hard for the patient, but it's also very hard for our loved ones.

Personally, my kids, my parents, my siblings, my family and friends are super worried about me. They also at times are angry and frustrated that not enough is being done to fix me or ease my pain.

### Judith

If I've learned something in this whole leak journey, it's that you can become completely disabled, enter a world of absolute horror and pain, and your MRIs will be completely normal.

### Theresa

The worst feeling in the world is hearing, your imaging was fine. It was fine. And you're like, no, like you, before you go to imaging, like you're like coughing and like trying to like, make sure that like, if there is something they can see it, but then they call you and they say, sorry, we didn't see anything.

It looks like you're fine. Because most people, they'd be so happy. Normal people would be so happy to say, a doctor say, Hey, your imaging was fine. Um, you can go on with your life. But for us, it's like, "Your imaging was normal" is like, it's like a nail for the coffin. Like you're just like, well, what am I supposed to do now?

How am I going to get anybody to believe me if you can't see it?

### Lee

Having a leak with normal imaging is devastating. You can see the doubt in our diagnosis move across the faces and hear it in the voices of the specialists. Our pain is worse than any image could ever show. And to have no proof or indication of the cause turns our world upside down.

### Anna

They found the leak on the MRI and I wanted to cry tears of joy once I got that confirmation email from my neurologist. I called my mom. I honestly can't think of like a happier moment because it finally, um, confirmed with evidence that what I had been going through was real and was, in fact, a spinal fluid leak.

### **Emma**

Here's some things I wish doctors knew. The first being that a negative imaging does not mean you aren't leaking and that doctors should be working with the patient, um, if the symptoms match having a CSF leak to further investigate this rather than dismissing it.

The second being, I wish doctors and nurses were more educated in CSF leaks. From personal experience, those uneducated doctors and nurses made those situations much more challenging than they had to be. And on the flip side, when doctors and nurses were educated in this field, they made my experience much better, wanting the best outcomes for me and supporting me and providing me the best care, and made it a lot easier on me

### **Mike**

You know, I had people in my family at the time who thought I was lying. You know, it's a real frustrating thing because they can't see it and it's such a tremendous amount of pain that you endure and go through and it's so debilitating.

I had to leave my job, and to have doctors not believe you, family members and friends not believe you, that's really, that's hard too. And that's a whole other element of this illness that really needs to be addressed.

### **Theresa**

My advice for doctors would be to believe your patients. Believe them. If they are coming in and they are telling you, "When I have a headache and I lay flat, it goes away," it deserves some sort of investigation.

Patients we really do, we suffer more when we can't get providers to listen to us.