

Jodi Ettenberg
Bridging the Gap conference
November 11, 2023

Patient Talk: On Living with a Persistent Leak

Thank you so much the introduction. Today I'll be talking about the tools and modifications in my home that have helped me live with a spinal CSF leak that has become chronic. I won't be able to get to all of them that I use, so at the end of the talk I'll be linking out to a website where you can find the ones I talked about, as well as the others, and where to purchase them if that's what you'd like to do.

These kinds of tools aren't just helpful with living with a leak, they're also helpful post repair or post blood patching, I really wish I'd had some of them in place when I was recovering from my patches, because I think it would have made things smoother and easier. Before I dive in, I'm going to talk a little bit about my leak journey and about acceptance, and then we'll move on to the slides. So, in 2017, I had a lumbar puncture done multiple attempts with 18 gauge cutting needles, and that's despite being pretty much kid sized. This is a kid sized top that I'm wearing today. The procedure was done without guidance, and it led to a spinal CSF leak that has since become chronic.

I wish I knew then what I know now, both about leaks and about needles, but hindsight is always 20/20. Unable to get patched locally, I was thankfully able to self refer, and I received four rounds of blood and fibrin glue patching.

On the fourth round, I went into anaphylaxis, the suspect being the fibrin glue, and needed an epinephrine shot on the table. Despite the dramatic nature of that fourth patch, it did seal me, and over the next weeks, my positional symptoms ebbed, and eventually, I was able to be upright all day. I was hiking, I was able to cook for myself, and though I took things easily, I was doing great. I was in rebound intracranial hypertension, but pretty mild.

It was controlled with a low dose of methazolamide. And then unfortunately, at eight months, I re leaked, and all of my positional symptoms returned. Given the way my fourth patch went, the fact that repairs just don't seem to hold for me, and some other complicating diagnoses, uh, like a mast cell disorder and a connective tissue disorder that are beyond the ambit of this talk, I've held off on further treatment for now and instead try to learn to live with my leak.

In terms of where I'm at now, when I first re leaked in 2018, I had almost no uptime. I was completely flat and eating flat as well. After prolonged bed rest, I was slowly able to get upright enough that I could go for slow walks and try and stave off as much of the deconditioning as I could. Eventually, I was able to move out on my

own with the support of family and friends who prior were taking care of me full time.

Last year, January 2022, I was up to about 7 to 8 hours of non consecutive uptime and walking quite a bit every day. Um, but unfortunately, I slipped in January and then my leak reopened in full again, and I've been flat for most of this year, trying to gain whatever uptime I could. Right now I have about three to four hours of non consecutive uptime.

That includes feeding myself, it includes showering, personal care, and doing whatever I can in terms of work in the morning, which is when my leak is at its best, and which is when I'm recording this talk. Having an invisible illness complicates things, too, because I look vaguely normal. I don't look like I'm leaking spinal fluid.

Sometimes I wish we could just glow purple or something to let people know, like, This lady has something going on that's not, not normal, but unfortunately it doesn't show, like many invisible illnesses out there. I'll be honest too, learning to live with a leak, as many of you know, is just not easy. I rely on humor in part to keep me afloat, but without grief therapy, I don't know that I could have coped or accepted with the complicated nature of what I've been dealing with.

And I struggled too, with what acceptance really means, because it's a word with so much baggage. I didn't want to accept that I needed home hacks for my disabilities. I didn't want to accept that my life of travel and food writing was over. I didn't even want to accept that I needed support. And as many of you have likely experienced, society places this weird weight on acceptance itself.

Over the last six years, I've gotten two very different but problematic takes. One is, okay, well, if you've accepted this, that means you've given up. You're not trying to get better anymore. Or people tell me, well, if you accepted it, then you can't complain about anything because you can't be negative at all since you, you said you accepted, you accepted what's going on, right? Both of those takes are just so bad. So binary. So unhelpful. So untrue. And so present on social media. Both are different sides to that toxic positivity coin. And because I hear from patients so often on this theme, I really want to emphasize.

Accepting does not mean giving up. Accepting does not mean resignation. Accepting does not mean you can't be negative anymore when things are hard. What it does mean is that you're not fighting against things you can't control and you can't change and what it does when you hit that place of acceptance is that it frees up all this space for peace, for creativity, for small joys where you can find them, for solutions for your problems, but it does that despite things being hard, despite things being very painful. Don't fall into the toxic positivity trap, because life has so much more nuance than the things we see on social media. For me, it took processing in therapy, like I said, the grief and the anger, to even think about home accessibility solutions, and all the while, of course, I still have hope that the field will evolve, eventually, to find a safe way to seal me one day.

I recently read a piece by a man who went blind later in life, and he said that blindness itself is not the disability. Blindness is an impairment. Where the disability comes in is that when he bumps up against trying to function in a world built by people with sight, that's when it becomes disabling.

Similarly, our world is not built for people who can't BLT, but hopefully with the slides I'm going to show you and the suggestions I'm making, at least your home environment can be better suited to your unique needs. So let's dive in. Moving on to the actual items in question. The basics, a sippy cup. I did use a bladder from a hiking backpack at the beginning of my leak, but unfortunately it got very slimy inside very quickly, it was difficult to clean, so I found a sippy cup the easiest option.

This is a toddler sized one, and it's easy to use, clean, and keep available, drink upside down as needed. Secondly, we have a... clomper, as I call it, a grabber device. It picks up things from the floor, it picks up things from the higher shelves, and it's useful both leaking long term and after repairs to avoid bending or twisting.

Third, we have my squishmallow family. You do not need to buy a family. I found that different sizes work best for me. Uh, I did use a pillow to hug after my patches to keep my back straight while I slept, but I didn't find that it was very comfortable. These are incredibly comfortable and can be used to prop up your shoulder, your hips, whatever is causing you some problems in terms of mobilizing it when you're trying to sleep. I will say that it is important to pick the right size. Left is Wanda the watermelon, way too big for me. Uh, the 12 inch size is the average size that most leak patients seem to do well with when hugging when they sleep.

Next up, the basics continued, A is a what it looks like a pool noodle, but it's actually pipe insulation. So it's like a pool noodle with a line down the side and opening. It's great for propping up things that are difficult to open. This is my panel for my heating in my unit, difficult for me to get to. I have it kind of on each side of that hinged door and it stays open. I also cut pieces off of it and put it on the both sides of my kitchen drawers because my drawers are difficult to open when the hinge essentially has a catch at the end and the large drawers are very heavy.

So this keeps the drawer from having that catch engage and allows it to essentially be, uh, accessible for me at all times. B is a whiteboard. I use this for my home care. Uh, I have home care twice a week that come in to do food prep to help with cleaning and other things that I can't do. I have a list of items I need. I have a to do list that of things that crop up in the interim of between their visits, and then groceries, basically anything else, even when family come and visit, they go straight to the whiteboard to see, is there anything that is available that they can do to help? C is a hook. Very inexpensive at hardware stores, on Amazon.

It's uh, just an adhesive hook that goes on the wall. Rental, apartment safe and friendly, uh, allegedly, although it did, it did still peel off some paint. You can basically use it to hook anything electronic or other things. This is my eye mask as well next to my bed. My plugs are quite low. This makes it a lot easier.

Next up we have the bathroom. Uh, my bathtub is quite high and. So I have a step that I use to get into it, and that is a non-slip step that works for the bathroom. B is a spring-loaded shower caddy. It attaches all the way up to the ceiling, basically, and in there you can see I also have travel sizes of shampoo and conditioner.

Those work great if the bottles are too heavy. C and D are for my faucet. My sink is very deep, and I have trouble reaching the faucet and the handle. It's hard to find versions of these that aren't either elephants or, uh, or ducks, but this is the adult version and it works very well for me to access my sink. E and F are essentially, uh, personal care items. E is a razor extender that allows you to essentially put the razor in the bottom, extend it, bend it, and shave your legs if that's something you'd like to do. My pregnant friends tell me this is also great for them. F is a lotion applicator. Again, I can't really access my feet.

It's very cold and dry here in the winter in Canada, and so that has been a useful tool for me as well. We're moving on to the kitchen. For those of you not in North America, our fridges are enormous and extremely heavy to open. Both the doors are very heavy, but also the freezer is usually a drawer, and there is no way that I could safely open it with a leak or even post repair, post patching.

So I have A and D, which are a fridge and a freezer. These are basically put on tables, and when home care or family come in, they help move fridge or freezer food into them that I can use during the week. B is just a quick note that just because it makes something more accessible, it doesn't need to be ugly.

This is the cord so that I can access the switch to be able to turn it on and off, but I used a cable cord holds basically into the wall to make a zigzag pattern, which I thought looked better than just trying to put the cord somewhere. C is my coccyx pillow, which I find takes the pressure off my spine.

I've used it since patching, and when I re leaked, it's very helpful in the car as well. E and F are, uh, basically kitchen items that I found very useful. E is a, is an oven. It looks like a toaster oven, but it's actually, uh, that and a convection oven. The oven in my apartment, again, very heavy to open the door, and quite low.

This is, saves on electricity, but it's also great to use in the kitchen as needed. And F is a workbench. So I decided to put everything on this very sturdy workbench from Ikea that lets me essentially get to what I need and not worry about instability on the table. Also in the kitchen, A is underneath that are wheels.

They're adhesive wheels. You can put them underneath. This is a knife block, but they can go underneath appliances as well. Very easy to move things around in the kitchen when they are on wheels. B is the opposite of my other cord that is more pretty. This is extremely ugly, but very functional.

Essentially, it is three sets of disposable chopsticks, elastic bands, and duct tape, because there was no handle extender that worked for the angle of my sink. This works perfectly. And C is lightweight pots and pans. They have a silicone handle that is easy to grip. And are very light and easy to use in the kitchen on to the more expensive stuff.

And I realized this is a privilege to be able to afford this. My business that I built to be passive income while I ate around the world, uh, has been able to be shifted into a business that works, even though I'm laying in bed and I can update it from bed. I realize that's not everyone, but I did want to highlight these two things that are great for my apartment. 1 is an auto slide. My patio door is extremely heavy. And even before I installed this, people without leaks were like, this is ridiculous. How do you, how could you open this? It is something that drills into the top of the patio door and you press a button. And it opens up with a pneumatic effect that way, a little motor in that device.

B is electric blinds. Again, the blinds in my unit, especially the living room, which are quite long, way too heavy for me to open and close. These are basically valances that go above the window. You press the button, and it only needs to be recharged once a year, which is great. Both of these are rental approved.

My building approved them. Even though it's a rental, I have to fill in the holes when I leave, but they said it was no problem. In the living room, just briefly on the step front, the same step I have in the bathroom is, is to be able to get out into my patio door, but A is an outdoor version of that. For those of you who also have patios or balconies and you want to be able to have easier access. It has holes. And so the rain can go through. And C and B are essentially couch access. For me, I don't find a couch with a line in it with the pillows to be quite comfortable. It usually hits me right at my leak site. So this is a bench cushion couch that a friend gave me. It's an old Ikea couch. But they are available these days in a lot of places, and they're often quite low being Scandinavian in style.

C are risers that the couch goes on and I basically I'm able to lift up the height of the couch to the 17 inches that I have found is best for me to be able to sit and log roll down. And finally, some odds and ends. Drawers, especially when there's no ball glides in them, are quite heavy to open when full with clothes.

I got these two dressers second hand on Facebook Marketplace. They're two Ikea dressers side by side and I've put my clothes in them so it's easier to open the drawers. They're quite light, considering how small they are. And finally, my workstation where I'm currently recording this talk. It's a standing desk also available at Ikea.

That's B. C is adhesive drawers that go underneath the desk. Again, just really useful to have things available to you at all times. Same with that bin you can see to the right, although I don't link out to it here, or I don't mention it here, but it is great to be able to have things on. Available to you, but not just cluttered.

And finally, D is a SAD lamp, a Seasonal Affective Disorder lamp. Because of my leak and because I'm basically upright for so little each day, and not outside in the light, in the sun, my unit also doesn't get much sun, I got this lamp and in the morning I turn it on to be able to basically tell my body, It's morning, we're waking up.

And I have found that really has helped to keep my sleep a little more stable. So those are my tools for now. Again. If you would like to see a longer list of those and the others that I use, please go to that website. For any questions as well that you have, I'm happy to answer them in the Q&A subsequent to this talk or by email is always great.

Thank you so much.