

## **The Territory and The Map**

### **Episode One: Storytelling to Survive**

#### **Introduction:**

A few months ago, I needed to drive somewhere I hadn't been before. So I did what we do now: I plugged in my phone, opened up the maps app, and typed in the address of where I wanted to go. I followed the phone's directions, beamed from some satellite directly into my car, and everything was fine—until I made a turn and found myself confronted with a lake of water across the road, along with a fallen tree, making it completely impassable. The voice in my phone hadn't warned me about this, and it protested when I tried to back up and take an alternate route. Eventually it successfully recalculated, and my journey continued without further incident. But it was a striking example of how, despite all manner of modern technology and real-time data being accessible to us, the actual experience of driving along those roads after a rainstorm was quite different from what the map said.

According to the map, there was a road for me to follow. According to my lived experience, there was a downed tree and two feet of water in that road. Which version of the road is more true, or more accurate, depends on whether you're looking at the territory or the map.

In the case of spinal CSF leak, it often feels like there's barely any map at all, only uncharted territory that we explore, painfully, hesitantly, on a daily basis. As we feel our way through the contours of this new land, we can try to explain it to others, but unless they, too, have had occasion to visit this unfamiliar country, they may have trouble understanding exactly what it looks like, what it feels like to live in it.

When we're lucky enough to locate a map for our care, if there is one, it may take us to far, out-of-the-way places. And while the directions it gives us are simple and clear-cut—take this test, go to this specialist, have this procedure—the experience of actually following those directions can feel confusing, precarious, and sometimes quite lonely, as though you are the only adventurer to have ever gone on this journey.

Welcome to “The Territory and the Map.”

#### **Andi Buchanan**

My name is Andi Buchanan and I'm the executive director of the spinal CSF Leak Foundation. I'm also the *New York Times* bestselling author of the *Daring Book for Girls*, the novel *Five-Part Invention*, and my memoir of living with a spinal CSF leak, titled *The Beginning of Everything*. With me is Dr. John Reiman, a trauma therapist who also experienced a spinal CSF leak. Hi, John. Welcome.

#### **Dr. John Reiman**

Thanks, Andi. Good morning. Glad to be here. By background, I've got three decades of experience as a state licensed and nationally, board certified therapist including EMDR certification. I've focused broadly on trauma and specialized in work with first responders, law enforcement, medics, dispatchers during and following overwhelming duty related trauma. I retired a few years ago after 30 years as a university researcher, teaching professor and technical assistants and development administrator in the area of deaf-blindness. I also spent the 14 months prior to September 13th, 2022, in “leak land,” and I'm going to use “leak land” as a reference to describe what for me was a so pervasive and so all of life inclusive experience that it felt like a, a distinct and strange land.

#### **Andi Buchanan**

We wanted to start this podcast to create a space to talk about spinal CSF leak in ways we usually aren't able to, moving beyond the map of symptoms and facts and firmly into the territory of lived experience.

Some housekeeping before we get started: This podcast is educational in nature and not intended to be a substitute for or construed as medical advice or individual therapy.

#### **Dr. John Reiman**

I'm floating ideas today, kind of a buffet from which you who are listening can choose in case anything sounds relevant. Your job is to see if anything possibly emerges for you that you sense as useful. Please don't take anything I say on before first running it through your gut and intuition.

### **Andi Buchanan**

Note that today we're going to be talking about the experience of having a spinal CSF leak, and it's important to practice self-care. So if you find this too difficult or too close to home, it's fine to stop listening and of course to seek professional help if need be. So let's get started.

“The map is not the territory” is a concept coined by philosopher and scientist Alfred Korzybski to describe the idea that our mental models of reality—the map—are not the same as reality itself—the territory. And this idea of the territory versus the map is never more compelling to me than in the setting of illness and especially spinal CSF leak.

It's one thing to understand when someone says, I have a terrible pain in my head. That's the map, the familiar experience of having a headache, but it's a completely different thing to experience that terrible pain in your head. The way that pain has a shape to it, almost the contours of it, the relentlessness. That's the territory. And it often seems with spinal CSF leak that we are in uncharted land and that we have to draw the map for ourselves as we go along.

### **Dr. John Reiman**

Andi, I'm struck by the power and fit of your word “relentless” to describe the territory. So much so that I and others with whom I have worked and continue to work who are actively leaking have felt a kind of identification with the leak that sort of blots out who I think I was pre-leak. Kind of a, “who am I?” question gets answered with, “a leaker,” even as in the background, I know that there's more to me than my experience of leaking.

Part of this is due to the brain having no reference in its memory networks to understand this new experience of leaking. And so it gets swamped. It's like trying to get your head, no pun intended, trying to get your head around something and not quite being able to do it. It so dominates conscious awareness. The territory of leak land can become quite all consuming.

### **Andi Buchanan**

Yeah, absolutely I remember for myself just trying to make sense of something that seemed insensible. You know, I think one way that we try to make sense of many things in our lives is through storytelling. Whether telling our story to others to try to convey our experience or to telling ourselves a story about what we're experiencing, to help us try to cope with it. It seems like a very human impulse. To try to shape a story around what's happening. Can you, can you talk to me about that?

### **Dr. John Reiman**

I think it is a human impulse to, to create a story, and we'll unpack more of the why and how of that as we go forward. From my own experience, I would just like to, at the outset, name sort of a number of “greatest hits” stories—and, and, and g”reatest hits” both has a meaning of “frequently told” as well as “frequently impactful.” So here is just a, a short rundown of some of the the products of the narrative making machinery. And we all have narrative or story making machinery.

Examples: “It's my fault.” “I must have made bad choices somewhere.” “The medical establishment's got this.” “There might be a problem somewhere, but could I be making a lot of this up?” “I'm weak, or I'm strong in the face of this.” Both stories. “I'm helpless and powerful—” I'm sorry, “I'm helpless and powerless in the face of this.” There's a bargaining story that often goes, “if I could just have done something or if I could just in the present do this or that, maybe it would go away.”

Another: “I'm alone with this.” And my most un unhelpful personal story was, “I'm better than this.” What an unhelpful story that was. So, as I was suffering, as I was confused, as I was judging how I was navigating leakland as not quite up to par, this story, “I'm better than this” arose, and it's not a very self-compassionate story.

### **Andi Buchanan**

But I think it's one that so many people can relate to. I mean, I know every, pretty much every bit of narrative machinery making that you mentioned in that list was something that I, I too thought and dwelt on and perseverated over and turned over and over in my own mind while I was leaking and then afterwards trying to make sense of everything. I think in a lot of ways, putting our experience into a story that makes sense is very soothing. Whether or not, you know, it's the ultimate explanation or the quote unquote real story, it's very soothing to have things make sense. Like in the same way that piecing together a puzzle is soothing.

**Dr. John Reiman**

Stories actually can have very positive value in their offering of human connection. When I tell you my story, I'm connecting with you. My storytelling could also be a salve for my pain. It helps me make sense of my experience. So I think stories have positive value. I think stories also can have negative value. To be particular, I think sometimes stories can be a rehearsal of mental distress recordings to the self that are not helpful and actually deepen the challenges in leak land. Said differently. It's possible that some of the storylines or the things I tell myself about my leak and about me are not helpful actually.

As a sidelight here, I noticed that in my experience of leaking, and I've seen this in the experience of others with whom I'm presently working, that the the messaging to the self, which originates in the frontal cortex, the thinking area of the brain can be colored by brain fog. I know that my own messaging and that that I see with others, the fog is such that negative beliefs seem more able to take root in fog than in clarity. And I think it's because the checks and balances on what I'm telling myself in the fog aren't as available as they are in clear air.

**Andi Buchanan**

I think it's so challenging to know what's real when we're leaking, and to know what we can trust in terms of what we're thinking and feeling because we are so compromised by brain fog and the kinds of neurological symptoms that we deal with. And it can be important to remember, I think that not every story you tell yourself is necessarily a true story, and not every story is helpful.

**Dr. John Reiman**

I first want to say kind of as I'm listening to our conversation that, well, concepts are, are frozen and reality is fluid. And what that means is that everything that we're saying, leak gland is such a fluid environment. And, and, and the pun, it's not a pun on, on spinal fluid. It's just, it's just fluid. It's subject to change. And in my experience, every time I thought I knew something or that I would come to some sort of conclusion, it turned out just to be tentative and, and everything keeps moving in leak land.

**Andi Buchanan**

Yeah.

**Dr. John Reiman**

I found that my own work in leak land centered on my tolerance for ambiguity. I kind of, I don't have the highest tolerance for ambiguity. And that was that was apparent in leak land when there were fewer answers always than there were questions.

**Andi Buchanan**

Yeah. Living, living in that gray area full-time.

**Dr. John Reiman**

Exactly, exactly.

**Andi Buchanan**

If you don't mind sharing a little bit about your experience, what was your spinal CSF leak story?

**Dr. John Reiman**

So I started getting headaches when I was driving for extended periods and noticed I was wincing every time my car hit a pothole or a rough spot in the road. Then for several months, I pretty much

had a continuous headache except for when I was lying down, which I could reliably do for relief. My symptoms included excruciating headaches, mostly at the forehead in between the eyes when I coughed, sneezed, bent over, turned in bed, moved suddenly, or stood up. And then rare but overwhelming headaches that would awake me in the middle of the night. When I think about my leak experience, those stand out as particularly difficult.

I also had ear popping light and sound sensitivity, blunted cognitive acuity. It interfered with my daily functioning and required that I would occasionally have to stop working. A general avoidance of all sorts of exertion. Any kind of exertion seemed to invariably result in a headache. And then intermittent paraesthesia, a sort of prickling tingling numbness on the top of my head.

I lived in fear of coughing or sneezing, and then I got COVID. And [with] COVID, I was sneezing and coughing continuously, and with each sneeze or cough, I would first try to get my hands up to hold my head in time in like a firm embrace so that I could minimize the pain. I probably didn't do much more than mitigate 10% and would often be, especially during the COVID period, on the ground in tears. Unable to—I was just brought to the floor by the pain.

**Andi Buchanan**

Oh my goodness. I, I mean, it just compounded one thing on top of another.

**Dr. John Reiman**

It did.

**Andi Buchanan**

So it, it sounds like you had a spontaneous onset?

**Dr. John Reiman**

Yes, it was spontaneous and inexplicable. One neurologist speculated it probably came from a sneeze, which I was doing fiercely in the hay fever season. The diagnosis of spontaneous intracranial hypotension was apparent to doctors from the start. Only one doctor steadfastly refuted this saying, no, you don't have a leak. You have occipital neuralgia, which I think I probably also had and may very mildly still have, though I think it's unrelated to a leak.

Every conventional endless image showed nothing for a year, and then in the 13th month, a brain MRI with and without contrast showed pachymeningeal enhancement, which is often an indicator of a leak. And at that point, a leak was differentially diagnosed based on my presenting symptoms. But no information about leak location. They couldn't find it. They tried MRIs of this type, they tried CT scans; could not find the leak. My neurologist said, okay, you need either to go to one of three centers. I chose one and then went and using, they used digital subtraction myelography, and for two consecutive days of real-time imaging under general anesthesia, two substantial and obvious CSF venous fistulas were located at T 10 11 and T 11-12. On September 13th of last year, I had platinum aneurysm clips surgically placed on each leak. Today, even as my body recovers from surgery, in rather inconsequential ways I might add, I shockingly have none of the symptoms that I detailed above. I'm frankly amazed to have my life back.

**Andi Buchanan**

Well, first of all, I'm so glad that you were able to get a diagnosis and timely treatment and that your treatment was so effective. It is quite a powerful experience to go through all that. So, was this story that you just shared with me, kind of this overview of what happened to you, was that something that you understood as it unfolded for you? Or were you only able to fully understand your experience afterwards?

**Dr. John Reiman**

Yeah. Yeah. I was in a pretty continuous state of confusion over the 14 month period. Even as I could kind of see frame by frame in a very piecemeal fashion, what was happening, I couldn't really integrate it into a whole movie. Now seven months post-surgery I continue to have unexpected little wisps of insight or understanding, you know, that periodically pop up and surprise me. I know clinically

as a therapist that loss, which is definitely a centerpiece of the experience of leaking, is something—the recovery from loss comes over a period of time in fits and starts and is a process. And I think it's important to name it as a process because people will say, oh, have you recovered, or will reference, I recovered. But I think it's a lengthy, I think that's a lengthy process.

**Andi Buchanan**

So it sounds like the story that you were telling yourself to understand your leak changed and evolved as you lived it. And that includes now, that includes the story still ongoing. Yes?

**Dr. John Reiman**

Yes. And such an important piece.

**Andi Buchanan**

I think it really is important to acknowledge that stories can evolve and that they need to involve as we learn more and experience more, and thus understand more about what's happening to us. You know, My own experience, it was also a spontaneous leak. And part of why I ended up calling my book “The Beginning of Everything” was because I kept trying to trace and retrace my steps to get to the start of it all. As if doing that could somehow make sense of everything. And even though the end of the book takes place about a year after my leak was finally addressed, I wrote the book while still very much in the middle of my story. I didn't have all the pieces of the puzzle together at all, and I still don't. But what I realized through that process is that no matter where you are in your story, it is impossible to see the whole thing. So even when you think you're relying on facts, you're still kind of always making things up and filling in the blanks and in that way, hoping to make sense of it.

**Dr. John Reiman**

Yeah. Yeah.

**Andi Buchanan**

Something I wrestle with as a writer, but also even as a parent in conversation with my kids is, is there a risk to telling yourself a certain kind of story? What if you tell yourself the wrong story? Is there such a thing as a wrong story? And what if the story you're telling yourself actually cuts you off from imagining other possible better stories?

**Dr. John Reiman**

So, about stories. Let me start by saying there is a story assessment tool that I learned from my daughter when she was like 10 or 11. I would say to her, you know, I would give her some unsolicited fatherly advice about something, and she would. Say, dad, could you just, what you just said to me, you know, could you just say it again?

And then I would repeat it and she would say, could you tell me how you think that was helpful? And actually that question, how is it helpful is a good first question. How is what I'm telling myself about my leak? Often, like other stories I may have told myself about myself across my life. How is that story useful?

And it's an interesting kind of question and one that the gut responds very quickly to. If I am storytelling and I can feel tightness arise in my body or confusion: Oh, okay. I know that that particular story isn't helpful. The final key, I think, in story assessment is that every story, no matter how adaptive or maladaptive really deserves gentle self-compassion. This can be so difficult. I really had to stretch in my most dire leak moments to get my hand up onto my chest and say something like, “Honey”— and the, the “honey” sounds like saccharine or, or something—

**Andi Buchanan**

Like you're patting yourself on the head.

**Dr. John Reiman**

It does, it does. But it is in a way a pat of self and it's

**Andi Buchanan**

Yeah

**Dr. John Reiman**

It's to self, "I know how painful this is, and I know you're doing the very best you can with what you've got."

**Andi Buchanan**

Mm, I love that.

**Dr. John Reiman**

Yeah.

**Andi Buchanan**

That's great.

**Dr. John Reiman**

I would say it really is the central piece. Sometimes it's really hard. It's really hard to get there.

**Andi Buchanan**

Yeah. I feel, I feel like every story that you tell yourself, it's not so much an attempt to to know exactly what's going on, but to discover how you feel. So I love that you say that you know about noticing kind of the physical feelings that you have when you're thinking about your story or, or telling somebody your story and, and using that as a, as a way to remind yourself to notice and, and give yourself some compassion, self-soothe, you know? Right?

**Dr. John Reiman**

Yes, I do. Um, I also know that getting to that compassion sometimes for me was quite difficult. I'm a highly educated, highly acuitus, seasoned psychotherapist and university researcher and professor, and for 14 months, I couldn't track where the bread disappeared to after I put it in the toaster.

Well, it's, it's hard to extend that compassion back to self. Like, "Hey, it's, it's okay, you know, you, you lost track of the bread from the time you put it in the toaster to.10 seconds later." Um, right. That's not an easy jump.

The other thing about story assessment that I found helpful is if I could just remember that when I'm in leak land, I am, uh—and this is going to be a very clinical mental health term—I am a taco short of a combination platter. The self-compassion, the extension of self-compassion to the story.

Correspondingly, the way to get out of such a harsh self-assessment for me was, "Oh, wait a minute." And you know, the reference "taco short of a combination platter" was, was sort of, if I could just remember that, that was really a good description of where I was.

**Andi Buchanan**

Right.

**Dr. John Reiman**

Um, I could be a little more spacious.

**Andi Buchanan**

Yeah, you have to be patient with yourself and sometimes it's difficult to do that. You know, I, I like, I like the "taco short" clinical term because it, it also, it takes you out of the grief you might feel about being unable to remember where the bread went when you put it in the toaster. You know, it makes, it helps you laugh a little bit. It helps you be kinder to yourself. It helps you be able to take that moment and just extend yourself some grace.

**Dr. John Reiman**

To employ another mental health, um, craft term, I, I worried that my "cheese had slipped off the biscuit." I, I thought I was in real trouble. and I didn't, I lost track of the fact that it was particular to the moment.

**Andi Buchanan**

Yes, yes. I mean, I, I wrote about this in my memoir about my experience, but one of my kids' favorite stories from when I was leaking was, you know, I would often, I still had to parent, I still had to run errands. I still had to get things done, even though I, you know, I couldn't really stand up for more than 15 minutes at a time. But I lived in the city so I could walk to the corner store, and, but by the time it took me to get from my home to the store, I would forget what I, why I was there and what I'd gone there to get. And I would find myself, you know, becoming extremely symptomatic and I would just go home empty-handed.

**Dr. John Reiman**

Yeah.

**Andi Buchanan**

Until one day before I left I had a brilliant flash of insight. I was gonna make a list, I would put it on my phone, I'd make a list, and I'd be able to go to the store and get everything I wanted. So I made my list. I went to the store. I got there. Everything of course started to go wrong. I had terrible head pain. I, I had a thing happen where if I was up for too long, I would just start crying. So I'm there crying in the store, completely lost, just not aware of what was going on. And then somewhere in my brain, I remembered, "Oh, you made a list!" And so I take out my phone, I look at my list and all the list says is... "Get stuff."

**Dr. John Reiman**

Wow. Wow.

**Andi Buchanan**

Just, I mean, I was simultaneously disappointed, overwhelmed, uh, laughing, um, and also terrified. Like was this, was this who I was? The person who thought, who could think that she had a great idea only to discover how flawed it was and how, how useless it was?

**Dr. John Reiman**

Yeah.

**Andi Buchanan**

You know, eventually this became a story that myself and my kids could tell each other and laugh about, but certainly, at the time it was very discombobulating. But in moments like that, I mean, what else can you do except give yourself the grace of just experiencing what you're feeling and going home and moving on, you know?

**Dr. John Reiman**

I do. Um, and giving yourself that grace, in very granular and practical terms involves, if you can get there—not everybody can, largely because we're programmed with "big boys and big girls don't cry"—but being able to cry is just an extraordinary gift.

**Andi Buchanan**

Yeah, I, I think it's really. It's a powerful gift you can give yourself to just allow yourself to be where you are and experience what you're experiencing. You know, I often felt like living through my leak, you know, I had a story that I'd grown up with, which is that I'm a strong person who gets through things, right? And yet here I was felt by this experience and it, it just made me think about, you know, I had to question myself like, Why is that story meaningful to me? And what do I gain from believing it? What does it give me to tell myself the story that way and, and what does it take away from me if I leave it out?

**Dr. John Reiman**

So that story is a great example. "I'm a strong person." Um, stories that cross our years and that we practice and rehearse again and again. I think appreciating that the onset of those stories, the inception of those stories—the stories evolved brilliantly and out of absolute necessity. In the case of "I'm a strong person," it could be, and I'm not saying this was your experience at all, that life was such

that taking on that story made it all seem navigable and palatable because I could cleave to “I’m a strong person” and hold fast to it in the face of all of what was going on. The challenge is to recognize that that brilliantly adaptive early story, “I’m a strong person,” later in life, in adult life, to recognize and to see that that story was helpful and can still in the present be helpful, but it’s not the whole story.

**Andi Buchanan**

Yeah. You know, in fact, I think often, especially for a story like that, that “I am a strong person” story, I feel like it’s often bundled with other stories, which are that, well, strong people don’t need help, or strong people don’t ask for help, or I can do this by myself, so it’s okay that I’m alone in this because that’s what strong people do. You know, the, the, the more layers you peel back of that story, you see how many other stories are bundled up inside it that may not serve you in this particular circumstance.

**Dr. John Reiman**

So well said, Andi. It’s, I think it’s also true that gender, culture, all sorts of other variables come in with that particular “I’m a strong person” to get mixed up and confound each other at points. So the stories are, are definitely layered in that way.

**Andi Buchanan**

We’ve been talking mostly today about the kinds of stories we tell ourselves, but I also wanna acknowledge how challenging it is when you’re called upon to tell your story to other people. Like, you know, for one thing with a spinal CSF leak, especially a spontaneous one, where do you even start? Before you can talk about what’s happening to you, you have to give a whole anatomy lesson about cerebrospinal fluid and the dura mater and the brain. You know it, it’s like trying to tell someone about what it’s like to live on the moon, like the rocket ship you took to get there, the astronaut suit you have to wear the helmet, the oxygen you need to survive—except first you have to explain to them that the moon exists.

**Dr. John Reiman**

Yeah.

**Andi Buchanan**

You know?

**Dr. John Reiman**

Yeah. Yeah. So looking at the reason that I want to explain my leak to you to another person is helpful. What am I trying to accomplish in explaining things to you, and what and why do you really wanna know? So I follow kind of a stepwise, iterative approach. I’d put a little out there and see if you really want more.

**Andi Buchanan**

Hmm. Yeah.

**Dr. John Reiman**

Often people will ask questions about my leak that they really don’t want answers to. Uh, when I’m in leak land, I don’t wanna expend a great deal of energy explaining or informing if you really to, well, just to be really frank about it, if it’s all about you.

**Andi Buchanan**

Right.

**Dr. John Reiman**

Um, if, if your questions are indirectly all about you in some way, your fear, your sadness, et cetera, I don’t think it’s fair to ask me to expend the vital and precious energy that I have, making you feel better.

**Andi Buchanan**

Yeah. Yeah. I remember telling people that my leak started with a cough, and some people’s reactions were to become very worried that it might happen to them, and ask me about what kind of a



cough and, you know, in a way kind of centering themselves in my experience, and also making it a little bit re-traumatizing for me to have to convey it.

**Dr. John Reiman**

Yeah. Yeah. I mean, it's sort of like, I don't want to, when I'm in leak land, be responsible for caretaking you. Yeah. Whether and why you want to know what's going on with me in leak land is actually quite transparent. We can see that in the relationship with another, if you really do, I'm all in, and I'll share what I'm able.

I often will ask an explicit question, um, is what you wanna know about the medical aspects, the symptoms, and so forth, around leaking? Okay—if that's what you want, I can direct you to resources that will give you information. Or is what you want to know about my experience, my pain, my suffering with the leak? Uh, if that's the case, I can share a bit more and then see where the conversation goes. But I make sure to tell you on the front end that conservation of my energy in leak land is important. And here's the key: I'm not sure how much bandwidth I'll have at any given moment to be in dialogue with you about anything.

**Andi Buchanan**

Yeah. And, you don't owe it to somebody else to, to be able to give a full accounting of your experience, even if people are curious. And I think it's also so challenging because as a person who is leaking, you're so close to it. I can't tell you how many times I try to tell someone the story of what was happening to me when they asked and just ended up in tears. You know, something about saying it all out loud made it feel somehow like something out of my control, even more than it already did, not knowing why it happened or how it would end—not being able to give satisfactory answers to their questions. You know, it just kind of opened me up to feeling more vulnerable than I was when I started the conversation.

It sounds like you have some good strategies there about keeping yourself safe while telling yourself or someone else the story of what's happening to you. But it's such a difficult thing to navigate.

**Dr. John Reiman**

Yeah. I think the first, assessment I make in dialogue with somebody about my leak is I'm going to judge you as safe for me to talk to about this if I have a sense that you really wanna know, a, as I spoke to a minute ago, but most importantly that you're not gonna respond to me with fixes, answers, recommendations, unsolicited advice.

**Andi Buchanan**

Yeah.

**Dr. John Reiman**

That's so hard to be on the receiving end of all of that. And again, it's really just a projection of the listener's fear for themselves. Yeah, yeah. Um, I'll shut down communication gently but quickly when I sense that the conversation really is about your imagined fear and so forth relative to that.

There, there also is in working in trauma for decades, there's a way where we can shield ourselves and one of my clients maybe. Eight or nine years ago came up with this brilliant visualization that she used. So, she imagined kind of this porous, transparent dome coming down over her. And enclosing her in a way, and somebody on the outside was saying things to her about what she should do or why, or just things that weren't helpful. And what she imaginably did was imagine that what could come in through the porous, this transparent membrane, what could come in and reach her was the love and caring and positive intention of the person who was trying to say something to them or reach them, and that what wasn't helpful would hit the membrane, fall down, and show up as little black powder in a track that went around the circumference of the dome where it touched the ground. And then that there was this vacuum that was on a track and the vacuum would come along and vacuum up all the dust, package it up, and that the dust would be sent off to the landfill.

She also imagined that what could go out from her to the other person would similarly be that, which was good and helpful in service of her highest good. There are lots of different shielding images,

visualizations, techniques, and practices, but I think it's important to be able to employ some kind of tool to keep ourselves safe.

**Andi Buchanan**

What a powerful image she came up with. I, I love that because it is true that, you know, many times when you're getting this unsolicited advice, it, if you put it through an emotional translator machine, it does come out [that] really what they're trying to do is help and they feel helpless. Right. So I, I love that she was able to come up with an image that, for her, really filtered out the stuff that was unhelpful and left her with something that she could take away as being helpful. It is hard to be in a gray area that other people feel helpless to, to help you with.

And that's the other kind of challenging thing about storytelling in the setting of a spinal C s F leak is, the story just continues. You know, it's not a tidy thing you can wrap up with a satisfying ending, even if you've had treatment that has helped fix your leak. It just keeps going even if your leak is quote unquote fixed.

It's been seven years for me since my leak was resolved and I still live with its aftermath, specifically in the form of mast cell activation syndrome, which is a chronic illness—and also the ghost of the leak itself, which could happen again to me at any time.

**Dr. John Reiman**

The ghost of the leak, um, I could just, even as you say it, feel my own gut tighten. Out of fear and out of remembering what that was like.

**Andi Buchanan**

It really seems to me that in thinking about story and spinal CSF leak, we, we have to be willing to be flexible. I. We have to be curious and open to the fact that our story can change. And while that might be frustrating, you know, because you'd like to know what's happening at all times, perhaps it's also hopeful to think about it that way

**Dr. John Reiman**

Yeah.

**Andi Buchanan**

Because thinking about story as a living thing means that, as long as you're willing to incorporate new information and question the story as it grows, storytelling—even just to ourselves—can be such a powerful way to process and understand what's happening to us.

**Dr. John Reiman**

Very much so. I, I recognize also that stories are pretty context dependent When I'm in the doctor's office speaking to a medical professional, by and large, my story is told in terms of my biophysiology. It's a physical accounting. It's a physical story, which it may not be my whole story by any means. It may just be a strand of my story. But when I'm in the medical establishment, by and large, I'm not speaking of the mental, the emotional, and the spiritual dimensions of my story. I'm rather locked into the biophysiology of it. I guess, stories, it's important to recognize, are many tiered and many tiered. I would both spell t-i-e-r-e-d as well as t-e-a-r-e-d.

**Andi Buchanan**

Absolutely. You know, the other thing that I remember when I was leaking, I was drawn to stories of adventurers. People who traveled to Antarctica had experienced the madness of cold and sensory deprivation or mountain climbers compelled to risk their lives, pushing their brains to the limits, or shipwrecks and crashes, poorly planned trips and failed expeditions. Survival stories essentially. And yet while I was leaking, being flat in my bed felt like the most difficult survival story of them all, not being outside exposed to the elements or off on some gr geographical adventure—just being alive in my bed.

And it, it reminds me of something Blair Braverman said. She's an adventurer and a writer who's most famous for being a long distance dogsledder. competing in races like the Iditarod. She said in a recent interview, "I always think it's interesting that as a culture, we've decided to locate survival stories in the

wilderness. We've decided that that's what survival means. There have been times in my life where I'm completely, comfortably at home. Going through things that are so difficult that it feels a lot more viscerally like survival to get through those time periods."

**Dr. John Reiman**

What a, what a clear— that's so clear and so powerful.

**Andi Buchanan**

I love that because it's true, we do kind of culturally locate survival as being something outside.

**Dr. John Reiman**

Right, right, right.

**Andi Buchanan**

And yet for so many of us, you know, this is what feels like life and death.

**Dr. John Reiman**

Very much so. And in that survival, sometimes in the midst of the most dense pain or suffering with a leak, I just had to retreat to a phrase that I actually put up over my bed and in my bathroom. And I'll just read what the phrase was.

"Things are as they are right now, painful and frightening, and I don't want them to be this way."

And now the important phrase:

"Here today, right now, in this very moment, where and how can I offer myself even the tiniest bit of ease, mercy, compassion, or kindness within or around this experience just as it is."

And I can remember in the depth of, of despair, in pain that I could do something as little as pull back a curtain and see the sky.

**Andi Buchanan**

Mm-hmm.

**Dr. John Reiman**

Or I could do something as as small as putting one hand in a certain way on my cheek.

**Andi Buchanan**

Mm-hmm.

**Dr. John Reiman**

So I just think that it does sometimes distill down to what feels like survival, and that there are the smallest measures that we can extend to ourselves that can be helpful.

**Andi Buchanan**

Yeah. Uh, that "Just as it is," that—

**Dr. John Reiman**

Just as it is.

**Andi Buchanan**

Yeah, that's, yeah, that's the piece that I think is so challenging, right? Because we wanna change where we are. We don't wanna be where we are. But you're right, you know: in that moment, there is an opportunity, an invitation, to offer something. The smallest, even the smallest bit of, as you put it, mercy, compassion, or kindness, even in that difficult moment.

**Dr. John Reiman**

Yeah. Another piece about stories is I find that they are reflexively told. Like, if I watch and notice what arises in my mind spontaneously and without intention, it's just, there it is. It's a story that's appeared. It's like there's a story-making machine that endlessly churns out a story or narrative about everything. Put simply, the mind kind of nonstop manufactures stories all the time, right? So I think the question becomes: what kind of relationship do I want to the story? If for example, I get a yes to the question, is it helpful, I might wanna buy the story.

### **Andi Buchanan**

Right?

### **Dr. John Reiman**

Allow and even encourage it to run. If there's nothing helpful and perhaps the story is actually not in the interest of my health wellbeing and safety, I might want to notice but not cleave to or attach to the story. This is way easier said than done.

But a meditation reflective or contemplative practice of some kind can really help making awareness—there's the key word, “awareness”—that there's a story even going on more readily apparent. Once I'm aware it's a story, then I have a choice about what I'm going to do with it, what kind of attention I'm going to give to it.

### **Andi Buchanan**

Now it's time for the part of the show we like to call, “Okay, now what?”

So we've been talking today about capital-S type storytelling. The being-in-the-middle of the territory experience of trying to understand what's happening to us rather than small-s storytelling, the map view, the bullet point version of what's happening. But sometimes it can be useful to have a bit of a map to guide you. So as you move on from listening to this, maybe just keep in mind a couple of things.

That stories can change, that stories are flexible, that the story of what's happening has many different versions, many possibilities, and many forms, and that's okay. That sometimes we're in a place that feels beyond narrative and that can feel scary. That you don't have to understand every single part of your story in order for it to be valid. That you don't have to tell every single part of your story in order to be valid. And that actually, you don't have to tell any story at all if you don't want to, even to yourself.

### **Dr. John Reiman**

I think that the key piece of story making to keep in mind is that there's no right story. There's no wrong story, there's no good story. There's no bad story. That every story is, in some form, our effort to be doing the best we can with whatever we've got at that moment. And it brings back in the self-compassion piece.

The literature is so clear that whether it's recovery from trauma, depression, anxiety; the central and key factor relative to recovery from any of those is self-compassion, and it's, that's such a, such a strong underlying piece.

There is a poem that I love that, at moments where I just, when I was most astir in it, I would read this poem and I could find some peace.

“Let go of what has passed, let go of what may come, let go of what is happening right now. Don't try to figure anything out. Don't try to make anything happen. Relax right now, and rest.”

Tilopa was the author of that.

Why this was so powerful was, there are moments in leak land where there is nothing to do. I've mentioned a moment ago just doing one tiny little thing, but there are moments where even doing a tiny little thing just aren't doable. And so this “let go of what has passed,” this whole “let go” piece—when all there is is to let go, I found this helpful.

**Andi Buchanan**

I think that's a beautiful place for us to end this part of our conversation. Thanks everybody for listening to us today, and on our next episode, Dr. Reiman and I will talk about strategies and practices for living in leak land.

**Dr. John Reiman**

Thanks so much.