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## **Patient Talk: Recovery is a Verb**

My name is Jen MacKenzie, and it's a pleasure to share my experience about recovering from a spinal CSF leak, something I'm in the process of doing right now. Actually, my whole family is in the process of recovery with me, and we're all making adjustments. While I was leaking, especially the last couple years, my symptoms were severe.

Along with debilitating head pain, I had brain fog and trouble finding my words, especially when upright. I would pause, struggling to find those words, and my family would help me by filling in the blanks. But now in recovery, when my family finishes my sentences for me, it's usually just called "interrupting."

I experienced a spinal CSF leak for many years, until my leak was recently found and durably repaired through surgery. Now in recovery, I'm confident I'm sealed and thankful to be significantly improved, but I'm still recovering from the toll leaking had on me. While my w-rd finding has improved, I am, however, still reestablishing synchronous communication between my brain and my mouth.

Because of this in-progress reality of recovery, I plan to read from my notes, as I share today on the complexities and considerations of my experience in recovery. A couple quick notes first. I do serve in a volunteer capacity at the Foundation, an experience that has enriched my journey and enhanced my awareness.

But I'm speaking to you today as just a patient: just me, my experiences, and the lessons I am learning. None of what I share is intended to be a substitute for medical advice. Next, I feel conflicted talking about recovery, that it can be frustrating. I might sound like I'm complaining. I'm so not complaining about having my leak resolved.

But while recovering, I felt that familiar struggle with uncertainty. For some, hearing there can be challenges that can arise, even after a long awaited successful treatment, it could be unwelcome news. For others, it might be validating to their own experience or cliff notes of what might be ahead. My hope is that sharing my experience in recovery can help increase awareness and equip others to better navigate their own journey.

What is recovery exactly? When does it start? How do I know what's going on? What will I expect? Who can help me? What do I tell people when they say, "how long will it take to be all better?" What do I tell myself? Will I ever be back to the old

me? These are all questions I've asked myself. Recovery is important to talk about because it can be complicated.

I found it comprised of unknowns, complexities, and some big feelings. The way we talk about recovery, the phrase "road to recovery," for instance, as a metaphor for the process of becoming healthy again, hints at the truth about the experience for many people with spinal CSF leak: that the largest part of recovery is not finally arriving at some static place, but the process of getting there.

My experience taught me there's two main types of recovery after a procedure. First is the initial recovery from the procedure itself. Second is the process of recovering, rehabilitating, and restoring health as much as possible from the impact of time spent leaking. I remember my first patch. Intracranial hypotension due to a spinal CSF leak was suspected, but we didn't have any imaging to prove a diagnosis.

Post patch, as I was wheeled into the PACU, I smiled in disbelief. For the first time since my onset, my vision was crystal clear. Once in the PACU, my husband joined me bedside, and he crinkled up a bag next to my head. Unbeknownst to me, he was testing my reaction. I had none. The intense, heightened hearing I had pre-patch was gone post-patch.

That first patch gave me a good five days of notable relief, and then all my symptoms came back. Following that first patch was nine more separate patch attempts at suspect leak sites. Scattered in between those treatments were various types of imaging, and nothing conclusive—until the most recent group of doctors working on my case spotted very subtle findings.

My leak was finally found.

In total, I made 11 trips out of state for spinal CSF leak specialty care. And it was on the last trip that sealed me.

These many trips taught me tremendous lessons. Navigating diagnostics and treatment. But my most recent learning experience lies within this current stage of recovering, since having that surgery that sealed me, a process I'm still in today.

Here's some things I'm learning about my recovery.

Recovery begins as soon as any procedure is over. For me, each recovery was a little different depending on the procedure, of medications used, and my baseline that day. And even though my care took place with spinal CSF leak experts, once in the recovery area, I often encountered staff that were not familiar with leaks treatments, how difficult a treatment day can be, and how delicate initial healing is.

At discharge, I received specific post procedure instructions and followed them closely. Those first few days following any procedure were spent flat, righting

myself, recovering from the meds and anesthesia, managing pain and nausea, avoiding constipation and resting, radical rest. I made a priority to ensure my physical movements protected the integrity of the attempted repair.

My initial recovery after surgery went really well. I had some unpleasant side effects to antibiotics. I did not get any sleep while I was at the hospital, and I was sore. But I was encouraged to note some immediate improvement to my primary symptoms. After discharge, it, that first week, it kind of felt like a dream.

Some improvement, some lingering symptoms, and a lot of fatigue, like it felt out of body. Following surgery, I was overnight two nights in the hospital. I did four nights in a hotel before flying home. I felt very fortunate to heal quickly from the surgery itself, have pain under control, no complications, and get home within a week. Assessing treatment success. By the time I had my surgery, I'd been on this journey for many years. Now with the leak site found and durably repaired, I had some high hopes. Success was almost too good to be true, but what, what is success? I spent the first month or so after surgery needing to lay flat for at least half the day.

This was taken one month post-op. I questioned, was I partially sealed or fully sealed? Was this normal? What is normal? I learned my body needed time. It's like I had all new wiring and needed time to reboot and sync up. I needed to be patient. Some symptoms immediately improved and others took more time.

I find the best way to assess treatment success is to gauge improvement of my primary symptoms. I look for trends over many days or weeks, comparing each to what they were at my pre-procedure baseline, comparing the old me to the current me, and not anyone else. To do this, I journal daily, checking in with myself about my primary symptoms.

I document how they've changed or are impacted by things like sleep, activity level, body position, or medication. I look for trends over many days or weeks, and this helps me not hyper-focus on the inevitable bumps on the road of recovery. Tangible progress, success, seems best observed when we look at recovery in months rather than days or even weeks.

Post-treatment, uh, it can be challenging to differentiate those normal bumps on the road of recovery and symptoms that require additional treatment. Of the symptoms I'm experiencing, which are complications of the successful treatment I just had, and which are indications that treatment didn't work for me?

I relied heavily on my journal to track patterns and symptoms to determine if they rose to the level of needing address. This has been difficult to do with limited access to a physician experienced in guiding the recovery process. After having a spinal CSF leak, the most common complication for me has been rebound high pressure.

Other complications involve conditions I developed during leaking or worsened from leaking. I'm thankful to have a very capable primary care provider who's watching today. And while they are phenomenal, it would be preferable and more effective to have comprehensive care from a group of specialists experienced in helping spinal CSF patients through the process of recovering after being sealed.

As the months pass by after my surgery, my symptoms, they're still confusing. Based on the sustained significant reduction of my most severe leak symptoms, and that I have mild rebound symptoms, I'm confident I'm sealed. But that doesn't explain all the other nuances that are just... weird. Some days I have extra head pain.

It's different though, not rebound, not leaking, but like an angry thunderstorm rolling around my head. Some days I'm really tired, and other times experience a spatial disconnection. I currently have mild rebound high pressure, or what I explain as "relative" rebound. It probably doesn't meet any specific criteria of being high, but for my brain, spending years in a low-pressure environment, my guess is that a fairly normal pressure maybe feels a bit high to me.

My mild rebound symptoms include ringing in my ears, wonky vision, and head pain that is mostly in my forehead, temples, and sinus area, which intensifies when I lay down, exert myself, or talk too much. I still have significant deconditioning to rebuild from, coexisting conditions developed during leaking that make the big picture assessment more complex.

In this phase, I continue to monitor my baseline, document my symptoms, look for trends, and manage the best I can. But like many patients, this work, I'm left to do largely on my own. Because I'm a complex patient, I choose to slowly ease into daily life activities, and I won't do certain things I did before.

For me, having more caution during my extended recovery is not a sacrifice, but an investment. Slow, gradual movements give me hope for staying sealed into the future. One of the best integrative activities I have found is walking outside. The sights, the smells, the fresh air, tactile feedback; it was super tiresome in the beginning.

But now I can casually walk and have a conversation. I can walk and talk. Something I could not do while leak. It's been almost a year since my surgery and I'm still noticing improvements. I'm still recovering. When will I be done? When will I be back to my old self? Is the old me still available?

Because we're all so unique with variables, presentation, and time spent leaking, answers to these questions are probably going to widely vary. I find it helpful to communicate with those that know me best and understand the daily struggle. I also find it comforting to connect with others in our community.

As I'm in this space of no longer leaking, but not my old self, there's reconciling to do. I try to accept and adapt to what is now, and not give up on the idea of complete restoration, but in an effort to be content, to meet myself where I am, and appreciate the process and the progress. I've also found it helpful to seek talk therapy for the trauma I experienced while leaking.

I try to be open to relearn and rediscover new ways of doing things. Being upright, all day, every day, for the first time in years, everything is different. It's an experience that forces reconciliation with my past life pre-leak, my existence while leaking, and my present, in-progress reality recovering from a leak.

My recovery experience has been a slow, incremental process, more nuanced and complex than I anticipated, with some setbacks. And while we work as a community to increase awareness and innovations that lead to quicker diagnosis and durable treatments, I feel like increased awareness needs extended to developing comprehensive care strategies for recovering spinal CSF leak patients.

While we as patients rely heavily on the specialist to trailblaze standards of care for general awareness to the greater medical community through conferences, collaborations, and published progress, those less informed on the condition look to them for guidance. I have a suggestion for our respected spinal CSF leak specialists.

Until spinal CSF leak programs are able to provide sustained, holistic, comprehensive care, supporting patients through each stage of this condition, diagnosis, treatment, and the process of recovering, I ask that you consider reframing the concept of treatment and recovery. After you've performed a procedure to close a leak, consider taking the position.

"My job is done, but THE job might not be done yet." Meaning, you've done your part attempting to seal the leak, but that doesn't mean recovery is certain, or that a leak or consequences of a leak are fully addressed. Additional treatment may be needed to further facilitate healing. This is not a criticism of the necessary and exceptional work specialists do in diagnosing and treating.

Rather, a needed signal for the greater community to understand additional care could be needed for those recovering. I hope sharing my experience in recovery today will shed light on the importance of increasing efforts to support the recovery process. By pairing our lived experience as a patient with the expertise of physicians, I hope we can bridge the gap in care, creating an environment for a more supported and intentional recovery experience.

Thank you.