

## The Gold Standard

By Logan Shannon

“You will feel like you’ve been hit by a truck.” I’m told this many times in the weeks and days leading up to surgery whenever I ask what it will feel like. I tell the surgeons and nurses who have never had this surgery that I have never been hit by a truck and ask if they have a different metaphor for what it will feel like to have all of my abdominal muscles severed, to have 60% of my liver and all of my gallbladder removed. Something a little less cliché. They laugh and say: “You will know what it feels like when you feel it.” And I spend the remaining days and hours wondering how to prepare for a pain I can’t imagine because I don’t like surprises.

My husband was diagnosed with Primary sclerosing cholangitis in his twenties, a rare disease I’d never heard of which attacks the liver. After ten years of slow and steady decline, his liver reached a point of failure so severe he had a variceal bleed and wound up lying in an adjustable bed in the ICU for a couple of days while I sat in a hard plastic chair curled in a ball watching him sleep, flinching every time an alarm went off. There are a lot of alarms in hospitals, and every time I heard a machine bleat out a warning, my muscles contracted and I made a fist. When fight or flight kicks in for me, I tend to lean towards fight.

After dating and then marrying a man who kept getting sicker, helpless to offer any assistance beyond making him food and taking him to regular appointments in which they told us, “yes he is still sick” and “no there is no cure,” I was ready to beat his disease into submission. When his doctor told us nearly bleeding to death meant he needed a transplant, sooner rather than later, I raised my hand like an over eager know it all; I didn’t really know the answer but was confident I could make something up that sounded convincing once they called on me. I wanted to help. I wanted to be of use.

My husband had a few surgeries under his belt before the transplant, as well as ten years of dealing with a chronic incurable illness, and many experiences with hospitals and anesthesia and pain that can’t be managed. I was new to the process, never broken a bone, never stayed in a hospital overnight. My experience with hospitals was centered around care-giving. I drove him to appointments and helped him get into the car after procedures left him disoriented, confused, and a little angry. I made soup and handed him stacks of his favorite bland crackers and wrapped him in a blanket while he stared off into space. When I asked him what it was like, to be put under, to wake up in pain, he shrugged. “Pain is relative, what hurts me might not hurt you.” He had always been so good about pain, pushing through it, rarely complaining. I hoped I would be good about pain too.

I tried to prepare for the physical pain before it happened by trying to recall pain from the past. Will it feel like a terrible period? The kind that wakes me in the middle of the night, the pressure in

my uterus taking my breath away, the stabbing feeling which sometimes follows, when my whole body feels like it's contracting? Once I sliced off the pad of my ring finger with a mandolin slicer while cutting cucumbers paper thin. I knew I'd cut it but couldn't feel the pain until I looked at my finger and saw the pinpricks of blood begin to well, the cut so sharp and so clean it took the tiny blood vessels a moment to recover from their own shock. When I know the reason for pain, when I see the cause and then feel the effect, I feel more equipped to handle it. My uterus is shedding itself, of course that hurts. I cut my finger because I'm a dum dum and wasn't using the mandolin guide, this makes sense. It's the pain that comes from nowhere, the surprise, that throws me. If I don't understand the origin I feel ill equipped to cope with it.

All the thinking about pain, the mental preparation, meant nothing when I woke up from surgery. It felt like none of those things individually, but it also resembled all of them combined. The first thing I noticed was my throat, rubbed raw from intubation, yearning for water I wasn't allowed to have. I used to get strep throat a lot when I was a kid, my lymph nodes swelling and closing up my throat, every swallow was an effort. This seemed worse by a factor of twelve. This pain, the shock of it, the surprise and confusion, made me deny the obvious. I wanted a complicated explanation. A breathing tube did this to me? Impossible. It felt like they'd shoved a handful of glass shards down my throat, rubbing my neck to make me swallow like you do when you give a dog a pill.

After surgery, every part of my body was in pain, as if all my nerves and muscles were sending alarm signals in solidarity with my cut up abdomen and my drastically smaller liver. In the early moments of recovery when the nurse pressed the button to give me a dose of painkiller, the pain didn't leave but I stopped caring about it. That's what they can't explain about painkillers because it's never the same for everyone, but for me, the pain was always there, like something attached to me. When I pressed the button for morphine, suddenly the pain was just another appendage I was aware of and was trying to ignore. Morphine let me attempt to sit up because when the pain hit I could look at it like an object, look away, and immediately forget it was there. Like The Silence in those Doctor Who episodes, every time I pressed the button I forgot, when the drug faded the shock hit me again. What the hell is that? Why didn't I notice this before? Then I'd press the button again and descend into a blissful ignorance of a pain that doctors and nurses describe as "acute."

There was a pain scale printed on the white board in my hospital room, the Wong-Baker scale, the one with circle faces and you're supposed to point to where you are, on a scale from zero to ten, compare your three-dimensional face to the expressions of six, flat, line drawings. Is your mouth a straight line with wide eyes? Are the corners of the line starting to turn down? Are there little frown lines around your eyes? Are there tear drops on your cheeks? At one point the pain was a solid ten, the wiggly line that was supposed to be my mouth was curved downward, the eyes squinting, the eyebrows fused to the eyelids, tear drops scattered across the circle's face.

When I felt like the "hurts worst" face it confused me. It wasn't because of the giant incision or the muscles trying to heal around the sutures holding them together, that pain I expected and was mostly managed and dulled by the drugs. That pain I could ignore. This pain originated inside my stomach, the product of bile acid pooling up, sending flames up my throat. It demanded attention. I tried to drink water in little sips, thinking maybe the cold liquid would temper the dragon beast camped out in my gut, but I was delirious from lack of sleep and couldn't remember the lessons from chemistry class. Was it wrong to add water to acid? Was I splashing acid all over the place?

Was there a baby dragon in my belly, angry at being trapped, bleating out its dissatisfaction, shooting flames up my esophagus like it was a chimney? It hurt to cry and trying not to cry hurt worse so I stayed as still as possible, my face crusted with salt, wondering if the pain would ever go away.

A few days post-op I secretly stopped pressing the morphine button, tired of the spins it gave me, tired of not caring, I was ready to embrace pain. The nurse who discovered my subterfuge sighed and gave me oxycodone in pill form and gave me instructions on how often I could request it, stressing that I should not put myself in the unenviable position of being behind the pain, chasing it, never quite catching it. But the oxy didn't relieve the bile reflux that was my primary problem in those early days of recovery, and it only made me feel nauseated. I was worried I would vomit and yank open my sutures.

One morning after rounds, I reached behind me to grab a pale pink bucket, certain I was about to fill it with water and bile and the little bit of toast I'd eaten earlier. My surgeon was talking to the team in the hallway and saw me reach and came right to my side, leaning down, his tall frame folding at the knees so he could look me in the eyes. "Are you in pain?" He asked and I shook my head no and then nodded yes. He looked at the bucket and asked, "Do you feel sick?" I closed my eyes and nodded, relieved he understood without me having to open my mouth, the pressure building, the waves of sickness culminating in a bitter taste, filling my mouth with saliva. He thought for a moment before asking me what I wanted to try, what had worked for me in the past. "Advil." I said gulping hard. "Ibuprofen." The nurse shook her head, "No way, that will never be enough." He looked at me again and I shrugged. "Give her the ibuprofen," he said. "We'll see how it goes."

The upper end of a pain scale arbitrarily decided upon and officially reached, I figured this was the worst I could feel. There were no faces after ten and so I would have to pull myself back down the line to eight, then six, then four. I took long deep breaths and held them and then slowly released them, leaning against the pain, daring it to hurt me more. The ibuprofen didn't take the pain away but it rounded the edges, turned my frown into a wobbly straight line.

Five years later I remember pain as an obstacle. If I didn't get out of bed I wouldn't heal, if I didn't heal I wouldn't be able to get out of bed. Functioning with pain that intense is not something I thought I could do and sometimes I didn't, sometimes I sat in it like it was a hot bath getting hotter, knowing if I didn't get out it would cook me alive and staying put anyway. Daring it to hurt me more. Like wiggling a loose tooth with your tongue, pressing against it, pushing the pain forward. Sometimes the pain we inflict on ourselves is refreshing, there's a clarity to embracing pain when you feel like you're in control of it. When you know you can make it stop if you just release your tongue. My dad used to say the best part of pain is when it stops, but we'd never feel that relief without enduring the pain first.

I try to manage pain now by comparing it to my new gold standard. This is not worse than having my body cut open, I think when I pass a kidney stone a few years after the surgery, the shock of pain so intense it triggers my vagus nerve causing me to vomit up the ibuprofen I had taken a few minutes before. "A ragged piece of calcium winding its way through my urinary tract is not as bad as abdominal surgery," I tell the physician's assistant in the clinic the next day when she has me pee

in a cup to check for traces of blood. She looks at me wide eyed as if I'm made of metal. It feels good to impress her, a woman who admitted she'd never passed one but heard it's not so different from the pain of giving birth. If I'd never been a living donor, maybe I'd feel different too, with nothing worse to compare it to, it might have been my 10.

I trace my scar sometimes, the visible one, with my finger, poking at the bright white line of collagen that runs from the base of my sternum to a curl around my belly button. It doesn't hurt anymore, but I always feel a tingle, a little twinge; I am not made of metal. I am skin and bones and muscle and nerves and scars. I am still afraid of pain. Our bodies perform so many tasks unconsciously, our heart pumps, our lungs expand and contract, our eyelids blink, these actions are mostly beyond our control because we don't need to control them. Pay attention to how you're breathing, how fast or slow, the rhythm, and suddenly it feels like you're in over your head. How will I ever be able to keep this up? When you stop thinking about it, the system takes over again and you become blissfully unaware of the process. Agreeing to accept an unknowable pain in order to save my husband's life was less like standing in front of a truck racing towards me, closing my eyes and bracing for impact, and more like a reflex. It felt like breathing, when I stopped wondering how I could do it, how I was doing it, I did it.

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**Logan M. Shannon has a BFA in Studio Art with a minor in English from the University of Iowa and an MFA in Jewelry + Metalsmithing from Rhode Island School of Design. She is currently writing a memoir about her experience as a living liver donor and is generally trying to convince everyone she meets that the liver is, by far, the best organ. Logan lives in New Hampshire with her husband, and their prolific sourdough starter, Seymour.**