

Now What? Community Reintegration after Brain Injury

Symposium

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Good morning. My name is Erin and I've been asked to share a bit about my recovery from a concussion.

I've thought a lot about how to approach this talk, how to share with you what has been one of the most profound times in my life. I sustained my concussion at a time when I was under a considerable amount of stress and emotional upheaval. I haven't been able to pull apart the independent pieces of my overall experience nor gain insight as to whether the concussion was the catalyst, or whether the concussion stripped me of my ability to cope with everything that was going on. A year and a half later, I'm feeling less and less that I need to understand how those threads weave together – just knowing that this time in my life has been deeply impactful, is enough.

In May of 2016, I was mountain biking on our local trails with two good friends when I missed a jump and crashed, with the left side of my face taking the brunt of the impact. I don't remember anything about the crash: I just remember waking up on my back, with my friend wiping my face, and shouting for our other friend, a doctor, to hurry.

I knew that the crash was pretty big: I could hear genuine fear in my friend's voice, I had no idea where my bike was and I had a really weird and intense all-over body sensation of wild vibration. After laying there for a good while and being checked over, adrenaline kicked in: I assured my friends that despite some strange visual happenings, I was ok to ride my bike out to the road. They gently helped me up, and I did just that.

The following morning, with some pushing, I went to the ER. I was meeting my family for a holiday in Utah the following day, and because of how I landed, I was encouraged to have my sinuses checked for damage before getting on a plane. X-rays showed that nothing was broken: I was told to rest and avoid any potential re-injury. I met my family in Salt Lake City, and spent the next ten days on a raft in the Greene River. I slept a lot, took it easy and did my best to stay out of the bright sun. All told, I felt pretty banged up, like I had taken a bad fall. As an athlete though, I wasn't worried: this felt like a pretty straight forward physical recovery.

About three weeks after the accident I returned to work as a manager for a small but busy non-profit. The first sign I had that something was off was that I couldn't type or text. Those finger movements, which prior to the concussion were automatic, suddenly required a great deal of

thought and focus. I had a very uncomfortable and somewhat alarming few days back at work, where I didn't really talk about what was going on but I made an appointment to see my family doctor, who suggested that I take more time off work.

I did this a few times over the course of that summer: I would feel better and be excited to return to work, only to do so and quickly realize that something was wrong. And the wrong was never tangible enough to do anything with, other than worry over. Sometimes it was my fingers not communicating with my brain, sometimes it was that I couldn't remember something that someone had told me literally a minute before, sometimes I saw and felt things that weren't there so I began to doubt my own perceptions: most often it was that I couldn't problem solve, think creatively or cope with any sort of discord.

I know that what I'm describing is not hugely atypical. We all have little moments where we're not quite sure where our brain went, what that person just said or how to untangle a particular knot. What was different for me was that these things were happening all of the time and often all at once; and they are nebulous enough that when you say them individually, or even clumped together, they don't really add up to anything. I can't tell you how often I sat in tears with my family doctor, trying to describe what I was feeling and experiencing. But there was nothing that I could point to, and say 'this here, this is exactly what's wrong'. I would try to pour a glass of water and miss the glass entirely while looking directly at it. I would walk into door frames as if I didn't know how big my body was, or where I was in space. I would pause at the bottom of a staircase, unsure of which foot to use first. I went for further tests at the hospital – everything came back clear.

The next 10 months of my life were exhausting. And terrifying. I spent more time in my doctor's office than I had in the previous ten years. I saw a psychologist, a therapist and two counsellors. I lost almost 20 pounds and my hair was falling out in clumps. I stopped sleeping. I was prescribed medications which I never took because I just kept thinking that I could figure it out. I experienced rage and destitution. I quit my job. I wondered if my family would be better off without me. And I was scared all the time, of things both tangible and things I couldn't even name.

I hid most of what was going on for me. A lot of that had to do with simply not understanding, not being able to make any sense of it and so not knowing how to talk about it. It was also about fear: I worried that if I shared everything that I was thinking and feeling, someone would actually pick up on the fact that my sanity was hanging on by a thread. I was also deeply embarrassed. I now know that I took a lot of pride in being described as calm, grounded and

competent: it was how people related to me and how I related to myself. So when I wasn't those qualities, and especially when I was the exact opposite of them, I didn't know who I was.

I was pretty certain that I was losing my hold on reality, I didn't have language to talk about it and even if I had, I was scared to show this to anyone for fear of validating it, I was embarrassed that the qualities people appreciated in me and that I appreciated in myself, were completely gone. So, instead of simply experiencing what was happening, I was in an all-out street fight to maintain my sense of my identity. There was no grace in this, and for those closest to me, it was gross and messy and loud. For all of the effort that went into holding it together, I was doing a pretty magnificent job of falling apart.

It took about 6 months for my doctor to use the word Anxiety with me. It came about after yet another tearful session in his office, during which I filled out questionnaires designed to see just how badly I was faring. According to the results, I was deeply anxious, a word that had never entered my life prior to this.

Having a name for what I was experiencing was pretty powerful. It gave me a container for understanding what I was feeling and offered a way of talking about it, which was cathartic. Unfortunately though, it didn't really change my experience, or alleviate my symptoms. One of my lingering physical ailments from the accident was a real aversion to looking at computer screens, so even with a diagnosis and a tonne of information at my fingertips, I had no desire to explore.

In preparation for this talk I googled symptoms of anxiety, which is strangely something I've never done. It's almost comical now as it shows me just how deeply immersed I was in my chaos. Heart palpitations, I stopped drinking coffee in the afternoons thinking caffeine was the reason my heart felt like it was going to jump out of my chest every night as I laid down in bed; difficulty sleeping, I was eating melatonin like candy trying to get rest; nausea and weight loss, a concerned colleague quietly approached me about having an eating disorder; feelings of fear, dread and panic: I often felt that my children weren't safe and that something terrible was going to happen if I wasn't with them.

Looking back on it now, the concussion, with its strange and disorienting physical symptoms, felt like an easy and gentle warm-up next to the wreckage of the anxiety.

Last summer, 14 months after my accident, I began to perceive gaps in the fear. I always described and experienced my anxiety as a predatory animal that was stalking me. When it was close, all of my energy went into bracing myself. Naming it made it instantly stronger. Sometimes it was far away. In these cases, I would do everything in my power to prevent it

from coming, but I was never successful. Other times, I wouldn't even know that it had 'gotten' me until after I came out of it. Coming out of it was a messy affair, and typically involved some kind of break down. My nine year old still teases me about losing my shit and ripping art off the walls of our living room. He laughs, we both do, but in the moment, it was totally surreal and I'm sure frightening for him.

Now, 18 months later, the sharp edges of all of this have been worn down, and everything feels softer, quieter. I now recognize and greet the anxiety when it comes, knowing that it WILL pass and that if I'm kind to myself, its presence in my life will be easier to deal with. Rather than an animal stalking me, I experience it as a fog bank. I do what I can to steer clear, but when it envelopes me and I can't see anything else, I focus on quieting my mind and anchoring myself in my breath: it's no longer a fight, but a reluctant dance. Thankfully, I am perceiving wellness and resilience in my life again, things I didn't know were missing until I began to feel them come back.

Reflecting on and sharing all of this gives me a really nervous feeling in my body; a physical memory of a dark time in my life. But, it certainly wasn't my entire experience and I need to share that with you, too. Strangely and beautifully, during this time of incredible upheaval where I couldn't even recognize myself, I learned a lot about who I am. Through the ugliness of wrestling with my identity, I came to recognize and cherish parts of myself, and not necessarily pretty parts, that I didn't even know were in me. Rather than fighting, I learned, am still learning, what it means to lean into my fear and vulnerability. What it means to let go and accept myself for exactly who I am in this very moment.

I had some tangible tools to help me through this. My yoga practice was life-saving, and I don't say that lightly. My bike was also a big part of my recovery. Both helped me find my body when my mind was tormenting me. I was fortunate to have a couple of close friends who were really ok just listening and witnessing. I began writing again. I discovered rich and powerful spiritual practices that will, I suspect, nourish me for the rest of my life. And I had care providers who, in the absence of concrete solutions, simply offered me their kindness and their presence.

The organizing committee very kindly asked me to share my story, and I am grateful. I hope that it offers you a way of thinking about acquired brain injury as not just a physical experience or an emotional experience, or a scary experience or a "whatever you've seen in the past" experience. I hope that it offers you a way of seeing that it can and likely is all of that, but that it can also be a whole bunch of other, unnameable things, and your willingness to bear witness to the entirety of that, can be a profound gift.