Two Dreams about Losing My Body

By Johanna Luttrell, PhD

Body my house
my horse my hound
what will I do
when you are fallen

Where will I sleep
How will I ride
What will I hunt

– May Swenson, *"Question"* (excerpt)

I remember first reading *"Question"* by May Swenson in college. Our poetry professor told us, straightforward, that it was about death. That the only thing we can really know about dying is that we lose our bodies, and the poem is a wondering about that—"What will that be like?" But here, the poet is not only wondering, she also fears. She asks, "What will I do?" (How can I be productive?) and, "Where will I sleep?" (Will I be able to rest?).

I recently had the experience of losing my body. One Saturday night in mid-autumn, just as the Texas sidewalks were finally giving up their summer heat, I was walking home from a concert with my husband, and I realized I couldn't feel my feet. The next day, I couldn't feel my hands or face, and by Monday I couldn't walk. When we went to the emergency room, I was diagnosed with Guillain-Barre syndrome (GBS), an autoimmune disorder that destroys the nerves. For me, it caused temporary but near complete paralysis. I could only move my arms very close to my body, like a Tyrannosaurus Rex. During the worst part, I had double vision and difficulty swallowing. I couldn't roll over, so it was hard to sleep, and I couldn't chew very well, so it was hard to eat. What was less important than sleeping or eating, but rather emblematic of the experience for me, was the fact that I couldn't do my own hair. Normally bouncy and curly, my hair looked sad every day. I also couldn't drive. In my non-GBS-afflicted life, I enjoyed being behind the wheel—it made me feel free. Now, after a couple of months of physical and occupational therapy, I am still struggling with some fatigue but have my independence and full range of motion back. GBS can be a lot worse. It can be life threatening when paralysis extends to the diaphragm, and patients need to be on a respirator for many months, sometimes in a lot of pain, and many people do not fully recover. Although I was comparatively lucky, the disease came out of nowhere, and it was very scary.

After my first hospital stay (I was hospitalized twice, for three weeks total, and then attended in-patient rehab for a week), I feared I would relapse and die. On

Friday, the first night I was released, I laid on my stomach on the couch, unable able to sit up, and I tried to feel grateful that at least the cushions did not smell like hospital. I overheard my aunt and my stepmom whispering to my husband that he needed to stay positive, for my sake.

On Saturday, I had a dream that I was wading in the water at my family's cottage on Lake Huron on Michigan's thumb. This is a place that's deeply familiar to me. I spent summers there with my large family. My mom, who passed away when I was 13, is buried in the cemetery in the property's woods. In my dream, the remembered landscape around the beach had changed—there were mountains on either side I hadn't seen before, a deep, lush green color, and the sun was hot, big, bright yellow and getting closer. I took time to sweep my hands through the warm water. I felt every sensation so vividly—a sharp contrast to my waking life during that time, when my whole body was numb. The dream was absorbing; I was so interested in the horizon's metamorphoses, the shapes of the summits and sun. I did not feel in any particular danger; I just felt curious, until I realized it was a dream about death. I cannot say how I suddenly knew I was in a dream about death, I just knew. Not feeling ready to die, I scared myself enough to wake up, trying to catch my breath.

The next night, I had another dream. I was driving and parked downtown in a city I didn't know. I was wearing clothes that were too young for me—white converse high tops, short jean-shorts showing tanned and toned legs, a jean jacket, and my hair looked fantastic, perfectly curly and bouncy. Once parked, I walked to a building where a work event was happening on the first floor, but I wasn't going to that; I was going to an event that portended to be more fun, on the second floor. I walked past my colleagues and waved. They were happy to see me and waved back and didn't seem upset that I was skipping their function. At the upstairs party, I made a bunch of new friends and played matchmaker between flirting couples. When I was done at the party, I walked back to my car, unlocked it, and drove away. Upon waking from the dream, I initially interpreted it as a wish to recover, to be back in my former state of independence and fitness.

At the time I had these two dreams, I was in an acute stage of my illness. I experienced a great amount of anxiety, which exacerbated the not-sleeping-or-eating problem. My husband was, rightly, worried about me and encouraged me to contact my therapist from graduate school, a very wise psychologist. Talking to her during this time marked a turning for me, in grappling with GBS. She encouraged me to see the time of illness and recovery not as something to 'get over' but as something to experience, to be present for, and to see what I could learn from it. She also encouraged me to write down my dreams. Whereas I felt scared and wanted to forget the first dream, she said there were insights to be gleaned from the experience of being so thoroughly in my senses, insights I might not want to miss. Of the second dream, which I initially wrote off as wish fulfillment, she noticed something more in the part about me happily skipping the work event.

While I was paralyzed, I could not work. In between doctors' appointments, I was mostly home on the couch. Before I got sick, I relied on work to regulate me, to give me routine. Even though I sometimes got overwhelmed with the goals and tasks, it gave me purpose. When all of a sudden I couldn't depend on getting up every day and being productive, unassailable anxiety and fear set in.

I am a college philosophy professor, and standing in front of a group of people who respect me gives me validation. More than that, I validate myself when I feel like I'm giving to other people: teaching, doing for, crossing tasks off lists. There is a good side to this: I've found meaningful work I enjoy. There's also a less-good side: I'm not very practiced in giving myself validation when I'm not doing these things. In the same way, I realized I feel like I'm not worthy to be in friendships or with my family when I'm not giving something to them, in the form of emotional support, labor, money, child care, et cetera—when I'm not pulling my weight, so to speak. Otherwise, why would people want me around? Cognitively, of course, I know that's wrong. I would never think another person was less valuable in the world if they weren't working and certainly not another person who is ill or disabled. But I couldn't give that same generosity to myself. There was a harshness in me.

Where did that self-directed severity come from? Maybe it's a mixture of Protestantism and capitalism, the cultural diet I grew up on, inflated by gendered expectations of women's worth in service to others. Some writers in Feminism and Disability Studies name and shame a capitalist society that only values people for what they can contribute, for being a productive worker, and perhaps those messages are directed toward women in a specific sort of way.* These missives of 'worth-in-productivity' isolate and harm disabled people, who have to work to rebuke those values, and create and give love and worth to themselves outside of their reach. I had read and strongly agreed with those writings before, but I hadn't had to live and feel them until experiencing GBS. What I needed to do then was give love to myself in the face of not being able to do anything for others. It helped that I realized my husband loved me even when I was lying on the couch. Concretely, self-love involved giving myself permission to rest and watch movies and let other people take care of me, for a long time, and not feel bad about it. Now, months out of the acute stage, giving myself permission still feels like such a relief to me. It's a gift.

I'm back at work now, but without the added burden of feeling like I have to use work to prove my worth as a human being. My therapist was right: there was something to learn as to why the fun event in the dream was happening on the floor above the work function. Happily, I've been able keep some of the lessons from when I was sick with me in my healthy life. I give myself permission to check out of my need to be needed, and check into rest. I'm able to rest even if I don't have the "excuse" of a life-threatening illness to explain why. The recovery period was actually sort of fun, in discovering what new thing I could do every day, how I could reach my arms a little bit higher each morning. To be honest, I didn't really care that I wasn't performing at my full capacity, as long as I was on the upswing. I also felt cared for and thrived under the steady attention of my physical therapists. The healing period was filled with gratitude and many naps. Resting and attending to my body has allowed me to hold onto the feeling of unexpected joy that I encountered in my dream.

I want to keep the death dream with me as well, although I still don't quite understand it. I found an unexpected paradox in it: the moment when I was most directly facing my own death was the same moment I felt most present in my body. And in the familiar but changed landscape—more vivid, more to experience—I connect to the poet's question, *Body, my house my horse my hound, what will I do when you are fallen…?* What will I do when I die? This experience has given me a hint, or at least freed me from some of the fear in asking.

* See, for instance, Gillian Giles, "You Do Not Exist to be Used: Dismantling Ideas of Productivity in Life Purpose," This Body is Not an Apology, March 5, 2016; see also Rose Hackman, "Women are Just Better at This Stuff: Is Emotional Labor Feminism's next Frontier?" The Guardian. November 8, 2015.

About the Author

Dr. Johanna Luttrell, PhD, is a visiting scholar of political philosophy at the University of Houston's Hobby School of Public Affairs, where she teaches classes in ethics, political philosophy, feminist philosophy, and general humanities. She received her PhD in Philosophy in 2013 from the University of Oregon, and she writes on issues of human rights, poverty, gender, and race. In the fall of 2016, after contracting a fever while traveling, she was diagnosed with Guillain-Barré syndrome. She is grateful for the awesome and steady care she received from the physical and occupational therapists at TIRR-Memorial Hermann in Houston, who see and care for the whole person. Now almost fully recovered, she is back to teaching and writing, salsa dancing, experimenting in cooking, connecting to her body through yoga at the YMCA, connecting to God and community at the Upper Room church, doing social justice activism, drinking Texas-sized margaritas at happy hours with friends, and being close to her husband. In the process of writing this piece, Johanna found that the humanities push for a [sometimes uncomfortable] honesty of expression, where she couldn't hide her vulnerability behind discipline-specific jargon. Thus, the process of writing a personal narrative was new, slightly scary, and very therapeutic. She believes the humanities give space to interpret the fullness of human experience, in all its complexity, allowing for the rich range of human emotion.