

A person stands on a wide, sandy beach at sunset. The sky is a mix of soft blues and oranges, with a large, glowing, pale moon in the upper right. The ocean is calm, and the person's reflection is visible in the shallow water.

THE RELUCTANT CAREGIVER

Reclaiming My Life After Caring for a Stroke Survivor

A Memoir

“A gripping memoir about the advantages of choosing self-care, even when it rocks our closest relationships.”

—Grace Kerina, author of *Personal Boundaries for Highly Sensitive People*

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Web of Care

March 2008 – Two Months After Stroke

I slam down the phone and burst into tears. Although it's been a couple of months since Tim's stroke, I am still trying to wrap my head around the web of care necessary for his recovery. Managing his disability insurance, his medical leave from work, his health insurance benefits, his speech therapy, his appointments with the neurologist, and his appointments with his primary care physician is a full-time job. How can I be the only one who is navigating and managing this? Why are all of Tim's providers not talking to each other?

I am still shaking as I think about the call that just ended. I was speaking with a customer service representative from Tim's health insurance provider. We received a statement in the mail saying the claim for anesthesia was denied because anesthesia is considered an "alternative treatment." *What the bloody hell? Have we gone back to the Dark Ages? Did they expect Tim to bite on a leather strap while a neurosurgeon extracted a blood clot from his brain?* The representative blandly assured me, "It was an error" and "of course the anesthesia would be covered," once I called the hospital and asked them to resubmit the claim.

If this were an isolated incident, I would probably laugh about the absurdity of it and move on. But it's not. Earlier this week I had a conversation with this same insurance provider about a single day in the middle of Tim's hospital stay that they were claiming was not covered by his insurance. He had insurance benefits the day before and the day after but *not on that one random day*. It made no sense. (It still doesn't.) That representative blandly assured me, "It was an error" and "of course,

all of the hospital stay would be covered.” I am starting to wonder if all claims run through a random claim-denial process, bumping out claims randomly for random reasons, with the hope that some random people will overlook them and just make the payment anyway. I wonder what people do if they are unmarried, unpartnered, or don’t have friends or family members who are able to step up and take care of this part of the process. I think I am starting to become very jaded about insurance companies.

I take a few deep breaths, blow my nose, check this insurance call off my to-do list, and then, with much irritation, add a call to the hospital regarding this claim to the bottom of the same very long list.

I move down the list and make another call—this one to a psychiatrist, a rehabilitation specialist who works in the area. A friend had recommended I consider having Tim work with this specialist so his rehabilitation care needs could be managed and coordinated by someone other than me. I talk for a while with an assistant, and it all sounds fabulous until they let me know that unfortunately, Tim’s insurance doesn’t cover this service. I choke back tears, thank her for her time and hang up the phone sobbing.

I wonder how I can return to full-time work. I’m not even sure I can return to part-time work. I wonder how I will be able to manage the paperwork necessary to keep him in good standing with his job. The requirements for short-term disability benefits, long-term disability benefits, and disability insurance claims are quite daunting—all requiring paperwork to be completed by the employee (or representative) as well as by the medical providers. How will I be able to manage to get him to speech therapy appointments three times a week and the doctor appointments that always fall during business hours, which are also *my* working hours? I feel the pressure of my own family leave coming to an end in a month unless I am able to spread it out with intermittent leave. The pressure from all directions feels completely overwhelming.

I take a deep breath and cross the physiatrist off my list and close my notebook. I can't make another call today. I know I need to rest. I know I am dealing with a system that is broken. The supportive web of healthcare in this country is an illusion that disappears the second you really need it.