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This Blurry Place of Better

By Sarah Cymrot

Two chairs are placed askew, gleaming black in the sunlight that cascades through the atrium glass. My friend Nathaniel and I tumble into the room, lugging our cellos, narrowly avoiding bumping into the doorway. There's a soft click of latches and the buzz of unzipping; the strings hum as we lift our cellos into the air. Nathaniel introduces the pieces to our audience. And then, with a breath, he enters on a high D. I join, driving the piece forward with soft bow strokes. Our harmonies interweave, swell, as doctors and patients pass by with the squeak of a wheelchair and the scuffle of a walker.

I imagined this scene for months and months after my discharge from the National Rehabilitation Hospital, where I began my recovery from a stroke that I survived at 15 years old. The doctors and nurses and therapists would gather round as we played, breaking out into a soft applause when we finished. *I'm done,* I pictured myself thinking, *I'm recovered.*

This moment has never happened.

I've cradled my cello countless times, but no matter how much I hope, my fingers buckle on the rough metal strings, and all I can create is a dull screech. Can my recovery ever feel complete without a moment of finality? When will it end, if I can always improve, but a return to the "before" is elusive?

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I remember the moment it happened. My whole body started to tremble, my voice slurred, and pressure built in my head. It felt like all life was draining out of me, like the tide was going out and I strained to stop it. When I reached down and touched my leg, it felt distant, numb. Most of all, I remember the all-consuming fear of the unknown and the known, the confusion of what was happening and yet the absolute certainty that it was something terrible. Within 15 minutes, I went from packing up to take the bus across town, buzzing with newly gained independence, to being carried out of the house on a stretcher, unable to move.

Barely half an hour after the life started to seep out of my left side, I was whisked down the halls of the hospital. Everything was fuzzy, soft—distorted by the absence of my glasses and the pain in my head. "It could be a tumor," I heard someone say, and I remember realizing that this was real. My life broke, divided into a "before" and an "after." Cold scissors pressed against my chest as they cut off my clothes, and I briefly struggled to emerge from the blur to ask them to stop. But while my body shifted and changed inside and everyone rushed around me, I sank back into the solidity of the present. Suspended in the moment when everything changed, I was protected from the uncertainty, from the precarity of the future and my growing distance from the past. I let the doctors monitor my brain, let the medications drip through my IV and my blood be drawn. My helplessness engulfed me, became me, cushioned me from the rapidly morphing world around me.

A CT scan revealed a white splotch against the dark texture of my brain—the evidence of blood pooling in the soft tissue. Not a tumor, but a hemorrhage. However, even once I moved up to the ICU and the blur of medical practitioners slowed, I strained to hold on to the world that was slipping out of my grasp. "Carrie," I whispered to my mom, reminding her to call my cello teacher to cancel my lesson. "Brickies," I mumbled to my dad, fixated on the community gathering that I had planned to attend that night. But I couldn't sit up, let alone walk out of the hospital. I was lucky to have survived. The bleed had damaged the right side of my brain, leaving me unable to move or feel my left side. My world shrank to the dim outlines of my hospital room as my favorite cello concerto played on repeat in the background.

On my 6th day in the ICU, I looked up at one of my physical therapists and asked for something beyond that room: to go outside. The sliding doors to the healing garden opened to their fullest, and I was pushed gently over the metal strip dividing the carefully heated halls from the blustery outside world. My eyes, which had been hovering partly closed, jolted wide open when the wind splashed against my face. My wheels crunched over the gravel pathway and the cold enveloped me, seeping through the pores in my bright yellow socks and the crevices left in the sheets that had been tightly wrapped around me. Wedged between two wings of the hospital, the small asphalt garden was filled with sunlight that reflected off the tinted glass buildings. The holiday lights that were draped on the backs of the deer sculptures were barely noticeable in the wash of daylight. Used to the warmth and soft noises of my ICU room, I shivered in the rawness of the world, acutely aware of how small, how delicate I was. And yet, the cars streaked by on the road below, honking and rumbling; the wind twisted around me. I was caught up in the vastness of the world, which tore me from my cocoon of absolute present, forcing me to think about what might come next.

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My subsequent move from Children's National to the National Rehabilitation Hospital (NRH) facilitated this look to the future. With a soft knock on the door—sometimes a steady rap, sometimes an intricate pattern—each therapist stepped into my room on that first day. "What are your goals for recovery?" they asked, one after another, trying to give me some agency over the coming months. But the answer felt obvious. I wanted to return to my life before: to long afternoons spent reading and family dinners and orchestra rehearsals and impossible math problem sets. I wanted to feel the vibrations of the cello against my chest, to walk down the street with my sister, to sleep in my own bed. I wanted to feel like myself.

However, while I was dreaming of this return to the "before," acute care at NRH was focused primarily on crossing the chasm of dependence. The goal was to build a bridge of basic function to allow me to return to the outside world. I had far to go. Most of my time was spent in bed because even sitting in my wheelchair was too exhausting. My mom dressed and bathed me, manipulating my body like one of an oversized newborn.

I spent my days in therapy, straining to move my immobile fingers and stumbling down hallways, supported by harnesses and steadying hands. These days were long and hard, and I cried almost every night, cradled in my mom's arms. But there was a comfort in the singular focus of the work; in that setting, recovery was the only thing that mattered. And slowly, oh so very slowly, I started to heal. A shimmering of movement appeared in my left side—first, I could shrug my shoulder, and next, lift my knee. One week I could twitch my fingers closed and, a couple of weeks later, I could gingerly unfold them. Then, almost two months into my stay at NRH, I took my first independent steps, feeling like a newborn animal as I tottered on weak legs.

“I can’t believe it’s over,” I said to my mom on the morning of discharge, a couple of weeks after those steps. I looked at the empty room, listening to the ambulances outside. Returning home to a first-floor guest room, walls covered with handrails, and a lanky blue wheelchair at the ready, I was certainly not recovered. Yet something had changed. Neuroscience tells us that at the moment of my bleed, a biological clock had started ticking. A brief window opened when I regained the plasticity of a small child, when therapy might force it to “rewire” and adapt to the damage. But as it began to slam shut, the fleetingness of this period became clear. “Recovered” was no longer a distant, almost fantastical, future point—I worried that I was as close as I would ever get.

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In a coincidence that can only be described as unfathomably lucky, our neighbor and close family friend happened to be a renowned physical therapist with an expertise in neurologic recovery. One of the first visitors to the hospital the day I was born, Susan was once again by my side at Children’s and NRH, and she stepped in to treat me when COVID-19 shut down the world.

“We are going for 100%,” Susan would say to me as I shifted my weight from one leg to another, her hands guiding me. “Of course we are aiming for a full recovery.” I was beyond the hospital therapy rooms and the green physical therapy mats that raised and lowered with a soft buzz. Instead, we worked on my living room floor—me often in my pajamas, having rolled out of bed at the sound of the doorbell. Susan rejected all expectations about what rehabilitation should look like, refusing to accept the idea of a fixed timeline of recovery. Instead, with over 50 years of experience treating stroke survivors, she introduced me to the idea that recovery is a process that would continue for as long as I was still working to get better.

Susan treated me every single day for the first sixty days of the pandemic and, although the outside world felt like it was at a standstill, my recovery was going faster than ever before. My fingers lost some of their floppy lifelessness and became straight and malleable. Moving hesitantly in my newly uncoordinated body, I learned to kick a soccer ball, then swing a bat. I lurched down the sidewalk in an initial attempt at running, clinging to my mom’s elbow. On a particularly emotional evening, I sat down at the piano bench and picked out the left hand of a Joplin piece I had been practicing pre-stroke. Weeks before, I hadn’t even been able to keep my fingers on the keys. Everyone was teary. “I know I am going to be able to play cello again,” I wrote in my journal that night.

And yet, this new phase of recovery was about more than just the tangible physical progress—it was also spent tackling the challenges that are much harder to track or define. It has not been the posturing of my arm or the lack of sensation, but rather the experience of recovery that has made my stroke feel so central to who I am. It has been the long periods of uncertainty. It has been the decision-making based on a future that was simultaneously foreign and opaque. And it has been the process of giving up on the "recovered" that I had once imagined.

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I began lifting my cello out of its case once a week, then once a month, then every couple of months. It was unfulfilling and exhausting. I couldn't dependably play one note. However, I couldn't help asking myself: would I be able to do it if I just pushed through and did it a couple hundred more times, if I looked beyond the frustration of the moment and thought about the possible reward? These questions extended beyond cello. I worried that I would resent myself in the future if I didn't work harder now when I had the time and support. So I was still dedicated to the idea of recovery—even if it was going to mean something a little different than that 100%.

That was until my doctor articulated the question that, almost eight months into my recovery, was becoming harder to ignore. "When are you going to be done?" he asked, gently. "There are only so many hours in the day…is this how you want to spend it?" Rehabilitation is a process of maximization—the push to achieve as much recovery as possible within the window in which it is possible. Susan had eradicated the timeline, giving me the gift of continuing my recovery for as long as *I* chose. However, that gift of choosing also meant I had to find an answer to my doctor's question. The months were passing, and my time spent on recovery was time *not* spent on something else. Was recovery still what I wanted to be maximizing? What was being lost due to that devotion? At what point would recovery end and normal begin? Medically, I've reached this point of "recovered" again and again. I became stable enough to leave the ICU, gained the independence that allowed me to come home from rehab, returned to school. Most recently, I reached another milestone as I sat on an exam room table, watching my neurosurgeon flip through scans of my brain. The veins seemed to dance, twisting and swirling as he scrolled. Looking up from the screen, he confirmed what my interventional radiologist had told me a week prior: the malformation that caused my bleed was no longer there. In the process of rupturing, it was destroyed. The chances of having another stroke from that malformation had become even smaller.

I walked out of the hospital after that appointment and boarded a bus that carried me through the bustling DC streets, just like I was supposed to do on the morning of my stroke. Although ordinary, the solitary commute felt like a return to the independence that my stroke had stolen from me.

Together, these experiences could be my "moment of finality." But it's also not that simple. Even with the malformation gone, the bleed cannot be erased from my story. It has become as much a part of me as the cello duets I once played with Nathaniel.

"Do the doctors think you are going to get better?" a classmate asked last week. I tilted my head. "I *am* better." I certainly haven't returned to the before. Nor have I reached 100%. I somehow simultaneously feel fully recovered and fully in recovery, living in this blurry place of better.

Sarah Cymrot is a pediatric stroke survivor and DC native. She is starting her first year at Swarthmore College in the fall, where she hopes to study medical anthropology and explore the intersection of illness, recovery, and identity.