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Personal Essay FINAL

I'm Not Sure How to Title This Sort of Pain

When I was a kid, Cerebral Palsy was the most important part of me: it was hours at occupational, physical, and speech therapy, it was crying when I didn't get picked in gym, it was losing sleep as mechanical, bionic-looking devices attempted to loosen my gastrocnemius, a feat ultimately performed by many rounds of Botox muscle relaxers. I was absorbed in my CP, and not by choice--it involuntarily existed as too much of my identity. I was introduced to teachers in a special way, placed in the back corner of the T-ball field, and ran around with a limp. I would cry to my mother about my invisible disability: I didn't have any noticeable issues until you slapped a few braces on the different trouble spots of my body, and then I got teased at school: I was "trying to get attention," and I wasn't cool because I couldn't play sports.

As I grew older, I began to hate the lack of muscle on my leg, hate the scars from my surgeries and hate my curvy back. I hated what CP kept me from doing, who it made me appear to be. It wasn't until I stopped growing and could ditch the majority of my plastic that I moved beyond throwing braces at my bedroom walls and sobbing through hamstring exercises. I know that I was not, and would never be, able to see past my setbacks with constant plastic reminders of my differences from others, no matter how hard I tried, and that's okay. Sometimes, radical change is needed to really move on.

I now know that I am not my CP, nor am I my stroke, my scoliosis, or my bum knee. I am not incapable; I am not debilitated by my surgeries or braces. I am me--I am Sophie Grace Charron, I hike through the woods with my dog every day, and I am worth more than 504 plans and flat feet: I am summiting mountains and conquering volcanoes with a smile on my face.

(written in June 2017 at Dover-Sherborn High School)

I wrote this reflection in my junior of high school for a prompt which involved "commenting on a setback you have had." I read this reflection while I was brainstorming for this essay about loss. I read this reflection, and I wanted to throw up.

It is painful to sit with in my Cerebral Palsy. I have been managing this disability since I was a baby – I don't remember a world without CP. I am CP. I am braces and operations and treatments that don't stick. I am debilitating leg pain and limps and migraine headaches. I am my stroke, and I am always at its will. I read the last paragraph of this reflection, and all I could think to myself was bullshit. How could I call bullshit on my own thoughts?

In October of my senior year, I had a surgery that was supposed to be the end of all my woes. Cutting the fascia around my calf muscle was going to give me freedom and mobility for years to come. The surgery went swimmingly, and the recovery was doable. I was jogging by spring and getting in ten solid miles each day by August. I was biking the length of the tree-lined Cape Cod Rail Trail and hiking the Green Mountains, hiking the Adirondack Mountains, hiking the Berkshire Mountains. Fresh air and whistling leaves brought me peace. Jogging at golden hour, as the sun melted around me and the dusk overcame the day, freed years of pent up frustration.

I was living again, or perhaps for the first time.

In my first weeks at Midd, I climbed to swimming holes and jumped off cliffs into the calm September water. I made laps around campus during sunset, watching as the sky became a canvas to pinks and purples and even electric reds. I decided I'd found heaven. The version of myself that pranced around campus in September would probably read my reflection from high school and sing of the work I had done to get to that point. I wish I could have that confidence back.

In the end, the surgery didn't work. You probably could've guessed that. Over the last six months, my condition has overtaken my personhood again. My muscle is significantly tighter than it was before the operation. I can't run or hike or jump off cliffs anymore. I can barely walk to class.

All my young adult life, I've lived through light. I think it's a product of being a photographer. Moments in my mind glow or droop; experiences cloud or shine. My best memories are sunrises plastered over the National Seashore in Cape Cod and rainbows strewn over the hills of Costa Rica. I love when oak trunks rest silhouetted by dim morning luminance and blades of grass settle under moody fog.

I lived through the brightest, best sunshine for so long. But now, I am living in dark skies. I am living in a hurricane. No one deserves the kind of strife that a sudden cyclone brings. My mom likes to remind me that not one person deserves the problems they manage, but that God gives certain people certain problems depending on how well he thinks they can deal with adversity. She teaches me I was chosen for, even gifted, my inadequacies. She teaches me to be strong and resilient. Nothing is allowed to suck, or even stink. I am meant to be a warrior, a success story, a superhuman.

I am not even allowed to be human.

I love my mom, I really do, but I wonder what the "overcoming" narrative has done for me. I don't know how to be self-compassionate or embrace any sort of flaws. Rather, I am terrified of my flaws. My "fun fact," whenever I am asked to share a fun fact, is that I ski on one leg. Carefully calculated, my fun fact tends to shock people and intrigue them. Off the bat, I give them the vantage point into my disability I want them to see. I frame it as a curiosity, not a weakness; I control the narrative to a harrowing extent, probably in order to defend myself from my own truth.

As I am writing this, I am in pain. I am in tremendous, crippling, unreasonable pain. I am weak. My leg fights against everything I want, instead choosing to rebel against class and practice and even sitting still and even putting on pants in the morning. That's the truth that I shield myself from: I have trouble putting on leggings. All these tangents I've been writing on and on about have done nothing more than hold off my reality like a wooden dam holding back a roaring, angry river.

When spasms usurp my body, I try to force my brain elsewhere. If I fight the tension, I quickly become exhausted physically and mentally. So, in truth, I don't fight anymore. I now know every contraction remains involuntarily strong whether or not I beg for it to end. My muscles work mercilessly, and they give me a lot of time to practice daydreaming while my body wages war with itself. My dreams take me to places I wish I could be, places I once was, places I am no more.

Sometimes, I imagine I am slicing fresh powder under my skis while my hair wisps out beneath my helmet. I soar through chilly Vermont air, off of jumps and onto rails, and then I get back on the lift to seize a million more runs. I relish the watery sniffles that coagulate under my nose, and I savor the small paper cup of processed hot chocolate as it slides down my throat, wrapping me up just like the dry heat of the after-ski fire.

Every once and a while, I put myself on Franconia Ridge in New Hampshire. I let myself trek up rocky White Mountain paths as I inhale the panoramic blue sky and exhale hours of burning quads and a sore back. My teeth sink into a delightfully stale peanut butter and jelly sandwich, and I smile at my dad, who knows just how happy I am to be here.

In most of my spastic dreams, though, I sit crouched in a rowing shell. I give commands, and my rowers respond with grace and poise. I hear one drive down the slides of the boat and one tap as everyone's oars come out of the stroke at the same time. Our hull glides across Lake Dunmore, and every worry we have lies collectively in the wake of our boat, then dissipates into the earth. We soar, five strong, motivated and beautiful women against an elegantly mountainous backdrop. We are a force, and I hold our energy at my fingertips as we dance across the glassy surface of the water.

In this dream, I am the most alive I can possibly be.

In reality, pain sucks the life, and even the humanhood, out of the most resilient people, leaving them with nothing more than tears and confusion and emptiness. I want to say spasms and cramps and shaking have taught me how to be a good person or how to manage stress or how to feel empathy. I wish I could say cerebral palsy makes me a better human as I swore just six months ago. I wish, more than anything, that I could be proud of what I am right now.

I don't know how to be proud of a body that doesn't want my intellectual capabilities to flourish or my desires to be fulfilled. I don't know how to love a leg that limps along behind me as if it doesn't really feel like being attached to me. I don't know how to love a body that chooses immense challenge over opportunity and joy and bliss.

I do know how to be proud of the version of me that was just like everyone else. I am proud of the version of me that strutted into the gym and whipped out an hour on the spinning bike during orientation. I am proud of the version of me that idled to class with minutes to spare in my first week of school. I am proud of the version of me that sat in a rowing shell all last fall and led strong women without having pain block her every decision and hold her back from being one of them: determined and strategic.

I am proud of the version of me that was strong because my neurons wanted to be.

I lost her. That's the truth. She is gone, and I can't seem to get her back right now. I am trying to smile and grit my teeth and move forward. I am trying to find self-love and compassion and hope. But right now, I guess I have to realize I'm mourning the loss of the person I was. I guess I have to give my brain, the one piece of me that still feels like it belongs to me, the space to stretch and reach and find peace. I need to let my brain, and maybe even my heart, rest, quickly, before it too falls into screaming, inexplicable pain.