“Once Upon a Craniotomy”

Ever since I was little I dreamed of living in New York City. The first movie I went to in a movie theatre was *Oliver and Company*, the Disney version of *Oliver Twist* but with cats, dogs, Huey Lewis, and the Big Apple. My obsession took off from there. According to a song in the film, “there’s always once upon a time in New York City,” and when I found out that I got accepted to social work school, I was thrilled to finally get to call the city my home.

It had been a whirlwind six weeks when I started losing my vision. It came in waves; first bright white light radiating from the tops and sides of my eyes and then it’s like confetti, sparkles across my vision like the world’s most terrifying disco ball. It strikes with seemingly no warning. The most terrifying time is on the subway. I stumble out of the train trying to hold my wits about me to find a bench to sit on with my head in my hands and wait for it to pass. At least in New York, you can wail in public on a bench and no one really bats an eye.

Everyone thinks they have a medical degree when you are sick. All of the sudden my friends, the receptionist at student health, my teachers, and people on the street know someone that this has happened to. I hear it explained away by the stress of graduate school even though I haven’t even been to class yet. My current life consists of sitting in front of my arctic turbo fan trying to avoid the stifling summer heat in my room and binge-watching *Dawson’s Creek* on Netflix when my eyes allow me. The biggest stressor I have right now is who Joey Potter will choose, Dawson or Pacey? Besides, I have been stressed before and it has never caused blindness.

I spend my first day of graduate school at student health. I am barraged with questions, “Is there a chance you might be pregnant?” I scoff out loud, appalled at the suggestion and practically scream, “Pregnancy can cause blindness?!” I get sent to the eye doctor for a series of tests and I decide that I must go to at least one class that day. I arrive at my afternoon class with my pupils dilated to the size of saucers. I approach the professor and explain that I just came from the eye doctor and I won’t be able to make appropriate eye contact throughout the class. I can tell I am making a great first impression.

There are emergency room visits, endless trips to student health, and being holed up in my room sitting in the dark willing my eyes to work. It has been three terrifying weeks of going blind in NYC when someone decides that I should have an MRI. It’s Friday morning and I don’t expect to get the results until the next week. I get off of the subway to four missed calls and voicemails that said the doctor needed to see me today and that they could not tell me over the phone. There is something on your scans. It can’t wait. I walk the longest walk of my life back into the neurologist’s office where she says words to me that I don’t understand. Brain Hemorrhaging. Malformed Blood Vessels. Swelling. Seizures. She tells me that it’s a small bleed, like that somehow makes it better. She keeps asking me if I understand. My brain is bleeding, and I understand nothing.

I make it in for a follow up scan of my brain and I get told that they don’t really know what caused my hemorrhage. The decision is made to monitor me and see if it gets any worse or I get any new symptoms. I get scanned and re-scanned. They can’t figure out what this thing is and the monitoring approach is not working for me. I am numb to feeling anything at all in those early days. I can’t really remember when I stopped eating, when I stopped going to bed at night,
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when I stopped waking up in the morning, when I didn’t have the strength to face the world at all and shut myself in my room, when I didn’t even turn the lights on anymore. I began to withdraw from anyone and anything that reminded me of what my illness was robbing me of. I didn’t get to stress about my date on Friday night or when a paper was due. I had to worry about what my next set of MRI scans might show or if my insurance would cover a $25,000 test that my doctor has decided I need. I don’t remember when I started thinking that it would just be easier for this thing in my head to explode and for it all to be over.

I start to fill out the paperwork, the third set that day alone. I remember the clipboard underneath my fingers, the smooth surface as the pen glided over the paper describing my medical history, providing the details of my life on one or two lines and a series of boxes to check off. Do you ever feel sad? Anxious? Depressed? Blue? On a scale of one to five, how sad/anxious/depressed/blue would you say at this moment? I remember wanting to cover the sheet when I filled it out like you did when you were a kid and you didn’t want the person sitting next to you in class to copy your answer. I remember how it felt to check off those boxes and then handing it to the receptionist at the desk. Was there going to be a separate line for those who had level one depression versus my self-prescribed four to gracing the border of a full force five level? The clipboard clutches my nearly level five depression and carries me into the doctor’s office that day. No one says anything to me about my answers.

I decide that I am not even sure that I want to know what’s in my head.

My final diagnosis was something called an Arteriovenous Malformation or AVM. It takes nearly five months and close to ten scans of my brain to reach this diagnosis. When the doctor tells me that I would need a craniotomy, a surgery in which a portion of my skull bone would be drilled away and a piece of my brain that contained my AVM removed, I feel relief but also a black expanse of nothingness. I am told that I was one of the lucky ones. I didn’t have a full rupture. I didn’t lose my sight. I didn’t lose my life. The surgery would fix it and I would be back to my old self.

The process of coming back from the surgery is unexpected and the pressure that I put on myself to feel better when I wasn’t is palpable. My skull cracks and pops as it slots back into place; healing from the inside out. I fight the nagging weight in my chest that threatens my ability to take a full breath and to the outside world I am a survivor. I am brave and valiant for having vanquished my illness and now I can just put it all behind me and move on. I do try. I go on dates, see friends, get my master’s degree, and start my first job. I continue to bury my pain deep down in a slurry of Advil and Chardonnay and denial. I am a coward and I can’t admit that even though I work in the mental health field, I have no idea how to ask for help or even know how much I really need it.

Suicidal thoughts had always been a low humming frequency in my life, waving over my mood like a vast ocean and pushing them down deep into the sand where no one could find them. My own little secret. During my illness, they came in shockwaves and static, intruding on my thoughts as I secretly hoped that this ticking time bomb in my head might end it for me and no
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one would be none the wiser. It would have been easier to explain that I had died from something outside of my control rather than of my own free will. I find that in the year following my surgery, my suicidal thoughts shape themselves into a plan in my head; a song clear as day detailing the way in which I could get out of the life I worked so hard to live.

I reach my breaking point and spend a night in the emergency room where they leave me alone on a stretcher without a pillow and tell me to get some sleep while they section me for an involuntary psychiatric hold. I start the process of finding the right mix of medications. One that numbs the pain but not my spirit, one that takes the hum of suicidal thoughts down to a murmur and the depression to a palatable inconvenience rather than an all-consuming threat. I fire a therapist for telling me that I am “beyond help” when I tell her that I don’t find any of the strategies she gives me helpful. I find the right one who doesn’t flinch when I talk about my desire to no longer be alive and helps me to plan for the inevitable, the next time these thoughts creep into the shadows of my mind. This is a start, but it isn’t enough. I lose friends but am honest to a select few. I tell them that I wake up every day disappointed that I am still alive, that my AVM didn’t kill me, and that I am not doing anything about it. I keep going to work and feel my hypocrisy burst forth each time I validate, normalize, and support others mental health crises while having my own. I tell any doctor that will listen that I am in pain every day. My head aches with the weight of what I am holding.

I slowly come back in pieces. I keep going to therapy and I keep taking my medication and figure out a way to make peace with my brain. I take all my sick time and vacation days. I listen to music and go to concerts again. I go back to New York. I didn’t get my once upon a time, but I make some good memories of the city that aren’t brain hemorrhages, craniotomies, and scars. I fall in love and am honest with my partner about my truth and they don’t run away. They listen and tell me they love me and that I’m not broken. I make new friends and try to forgive the ones that couldn’t be there for me when I need them to. I wake up every day and make the choice to stay alive. Some days it feels easy and others I can barely lift my head off the pillow.

Before I know it, it’s been seven years since the surgery. There are days when I wake up with the buzzing in my head and the thoughts about dying creep back in. I don’t push them away anymore. I sit with them and let myself feel okay with not always wanting to be alive. I’ve never returned to who I was before I was sick, and I know now that I never will. I’m still doing the hard work of how to incorporate what has happened to me into the life that I have now. I decided to get a tattoo as a reminder to myself of what I had been through and how far I have come. It is an image of a dove with an olive branch in its beak perched on top of a weathervane. It is a reminder to be at peace with the change of direction in my life and that sometimes despite the unrelenting wind, I get to decide where I land.