



## JOY COMES IN THE MORNING

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# KING OF THE MOUNTAIN

Amy-Joy Thompson, Class of 2016

*Author's Note: This first-person account is written in the voice of a patient who left a great impact on me. We talked for 3 hours about his incredible life living with an extremely rare and (up until recently) very misunderstood condition. I felt honored to speak with such a vibrant and perseverant person. I hope that you will learn from and enjoy his story as much as I did.*

“Most things break, including hearts.  
The lessons of life amount not to wisdom—  
but to scar tissue and callus.”

-Wallace Stegner, *The Spectator Bird*

I tried to deny that I was all that different, but the playground kids would always manage to remind me—painfully—otherwise.

Granted, I'll never claim to be bright. I loved playing King of the Mountain when it probably would have been wiser to hang back with the group of “nice girls” who pitied me, girls who would invite me to study with them in the library after school. Instead, I would brush them off and follow the other boys into the patch of woods behind the school. The rules were simple: climb onto the log, grab someone around the waist, hurl them to the ground, and repeat. That one day, I swear I was Captain America,

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my favorite superhero—I sent every kid soaring and scabbling face-first into the rotting leaves. I lifted up my spindly arms and roared.

I didn't see Benjamin, ever the sore loser, grab me by the ankles from behind. My feet went tumbling and my torso snapped sickeningly against the log. I crumpled to the ground on my back, and to prove the twisted point, he punched me in the chest, hard. I heard a revolting crunch and felt a wave of excruciating pain that made me convulse against the ground. "Oh, did I make the little King crack? Looks like Humpty Dumpty fell off his wall..."

I thought about correcting him ("It's Humpty Dumpty, idiot!"), but then reflecting on my misshapen body, and my dumpy hand-me-downs, the variation was probably intentional—and it stuck. When I came to sometime later, it was dark and I was alone.

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I first heard the term "Osteogenesis Imperfecta" in the movie *Unbreakable*. I shoved it into my sister's hands and said watch this. My entire body shook as everything finally made sense and came crashing down upon me. Our curse at least had a name.

My youngest brother has it, too. My mother wailed that it was her fault as the doctor ran out of the hospital room with a small cocoon of bloody sheets in his arms. I was sitting on the cold floor in the hallway, and snuck a peek through the door to see my mother sobbing. My father nursed his own hand after my mother had presumably cracked his hand during the delivery.

When I finally met my brother, he was a bundle of bandages, weird angles, and a web of skinfolds, encased in two diaper casts. The doctors reported that he had been born with 42 breaks below the knee. I shifted my own bandages uncomfortably, shaking my head pityingly at my family's sore luck and sighed.

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I was the least cool kid in class somewhere on par with parasites and the plague. As Dad was more generous with the strap than with wholesome fatherly wisdom, and Mother was too busy tending to my brother's latest fractures to notice my existence, I searched for other ways to keep myself sane. I tried football. During the first practice, a kid gave me one generous shove and cracked my collarbone. I tried working at a swap shop in 4th grade, and slipped on a puddle, splintering a vertebra. The store owner glared at me writhing about on the floor and snapped, "Hurry up and clean this before a customer slips!" A customer finally took pity on me and called an ambulance, and I was promptly dismissed from the establishment.

As it seemed wise to spend the rest of my childhood trying to be invisible and stationary, I resorted to the safety of my three-hundred comic books—especially Captain America. My sisters, Pea Pod (my flying squirrel), and my uncle have also kept me on my feet. My uncle gave me my greatest escape: the water. Every Saturday I'd wake up at the crack of dawn with a 5-gallon bucket, tennis shoes, a pair of cut-off shorts, and a sack. He took me water skiing. I've never felt so unbreakable! I wound up shaving off one of my skis to a point and I dubbed it my Uniski, for even if one leg was aching, I could balance on the other. Then at the end of skiing, I'd push my brother along the pier as he drug the dip net beside his wheelchair catching crab for our Sunday night boil. I owe my uncle the best years of my life.

The rest of those days—they belong to my wife.

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The first marriage was also a casualty of disease. It snapped from the strain, and neither of us had the means to splint it or the patience to let it heal.

My second marriage though...they don't make them like Joyce anymore. She was the most beautiful woman, and it's more painful than any fracture to think of her now. While she lay in hospice, she made friends with every nurse she met. I stayed by her side almost every moment, but when I couldn't

## KING OF THE MOUNTAIN (CONTINUED)

take it anymore, I left and returned with a bright yellow and red tattoo over my left chest—a picture of Betty Boop, her favorite character, with “Joyce” in a curled banner beneath it. I unbuttoned my shirt that was tight around my barrel-shaped chest, and revealed the tattoo.

She lay there, speechless. As a Catholic, she never did believe in tattoos, and I wondered if I had insulted her—but later, she asked one of the nurses if she could have one too. It just so happened that the nurse’s husband was a tattoo artist. He gave her one that mirrored my own, with “Butch” (my nickname) on the banner.

Two days later, she passed in my arms. I would have taken a thousand fractures over losing my best friend.

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My sister and cousin kept me going emotionally while the doctors kept me going physically. I’ve had more vertebroplasties than I can remember. At one point, a doctor did an x-ray to scope out my rotator cuff and said, “We have a problem.” They saw a lung mass, which for a brief moment, I saw as so ironic that I burst into a fit of laughter in the office and the doctor thought I was crazy. But alas, that too was related to the disease—somehow some bone cement had gotten lodged in my lung and is floating around in there somewhere. I have 4 pins in my arm that won’t hold, and my knees are made of more bionic material than bone. So much of me is metal that I might as well be considered a walking superhero with a metallic skeleton for a suit.

Despite the fact that I am on a first-name basis with most of the orthopedists in this city, I still feel like a foreigner in the emergency room. The last time I was there, I had broken another bone in my back. The convulsions this time just would not let up. I keep a small canister of Percocets that I break in half and store on my belt to try and last me the month, but they didn’t even begin to touch the pain. The medical students in the

ER rolled their eyes when I declared my pain level, and denied the existence of my condition. Oh, I know the damn ER isn’t connected to the hospital system, but all they had to do was ask for the records and they would know that I’m not one of the pain junkie pill mill vampires that has made the rest of our lives miserable. Just when the convulsions started to die down, a tech tried to move me—and I swear I wanted to wring his neck. The pain flared up all over again, and they again rolled their eyes when I screamed.

It makes you hate people, you know. It really does. These are the same people that, standing outside of my brother’s deathbed in the hospital said, “Hey, did you see that guy? He looks like big Buddha.” I stood up next to my broken brother with his barrel chest, and with fire in my eyes said, “That Buddha is my brother.” They simply walked away.

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This is Superman’s kryptonite. I try to make the best of it—I used to build and fix fiberglass boats before my disability wouldn’t let me anymore, but I was damn well good at it—and I still go fishing and hunting, and I swear buck fever is real and is better than any medicine—but sometimes you want to give up. I wish I hadn’t had this disease. The ridicule leaves you scarred.

But I’m still trying. I thank God for my daughter every day. I didn’t want any children, but I am so glad that we had her—every time she hit a cabinet or fell to the ground, I scooped her up to check that she was okay. Every cry or whimper had me running in the night to check. I never got any sleep as a parent. But thank God—she is fine. She has three boys now, and they are all fine.

Maybe the generational curse has come to a close. Maybe my superhero power as Butch was to put an end to this cycle.

I guess that makes me the King of the Mountain—I’m the last one still standing. ■

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