

Monologue

I had a brother who had Muscular Dystrophy. He was born without the gene that's responsible for a particular protein called dystrophin. Dystrophin anchors the muscle cell to the extracellular matrix of the muscle tissue. It's an architectural protein. He didn't have it.

It's a progressive illness. You don't notice anything at first. Just a normal happy, healthy baby. Then, as a toddler, maybe you notice something. Maybe he walks like he's had a hip replacement. Like one leg shorter. And then he's using crutches to get around. Then, a wheelchair. In Chase's case, he had an electric wheelchair. Which was cool for me. I got to ride on the back a lot. We cruised around the neighborhood, hunting lizards in other people's yards. Blowing stuff up with firecrackers. Not lizards, usually. I actually think that happened once. I have a dim memory, like just a whisper, just a faint outline, like I've tried to erase it. Repress it. I'm not sure.

So, first the wheelchair, then a the gradual loss of strength. I'm not sure why it's gradual. 10 years or so, and then you die of pneumonia. The diaphragm is a muscle. The lungs are not muscle. They're just fleshy lumps that are moved by the diaphragm and it weakens to the point where it can't move the lungs, push on them, squeeze them, help the alveoli, the microscopic air sacs that exchange gases (Co2 for oxygen) and keep us on the move. So, the air sacs fill with fluid (microscopically) and the oxygen can't get to where its needed.

He died at 23 of lung complications.

I wanted to tell a story about him. I came up with a couple of scenes. Mere pittance.

In this first scene, I am about 10. And Chase is 15. We are playing in our house and I did something to piss him off. I was his servant, like a lot of little brothers. But unlike a lot of little brothers I was also probably his best friend. So, that upped the stakes. He couldn't just slug me and take off to his buddy's house.

Whatever it was I was guilty of he said that he was going to ram me with his chair.

He had done it before. Big brothers are known to put little brothers in their place. Usually, its effortless and so casual so that you have to be really watching to notice the little brutal shove, the hurled projectile bouncing off the head.

So, that's how the drama begins: a typical fight between brothers. Being the smaller, I ran away. I ran up the stairs, all the way up, and hid in my room. I was feeling very desperate, scared, even though I was (obviously) safe where I was. I have a distinct memory of hammering away at the eye hook on the screen of my window, trying to escape. It was the second story but it didn't look that high up. 15 feet maybe. I couldn't get the latch to budge.

There were two sets of stairs in our house. A circular staircase and a regular staircase. The circular staircase was metal and it made this clanking noise as you descended, but the other one was carpeted, and therefore quiet. But it didn't seem to matter. He somehow knew where I was. I went back and forth, back and forth, between the staircases trying to sneak back down. I don't know why that was my goal.

Maybe it was because boredom is so unbearable when you are 10, and there was nothing for me to do upstairs. No TV or refrigerator. I don't know. It doesn't make sense because other times I was happy to play in my room for hours. It was like a Beckett play. We needed each other. Hamm and Clov, those are the names of the Beckett characters in *Endgame*. Hammer and Nail. We needed this drama like a Hammer needs a Nail and vice versa. Otherwise, there's nothing happening.

So, this went on for at least a couple hours. I would sneak down, listening for the low whine of his electric wheel chair when it's just barely inching forward, and I'd start to make a run for the front door or back door and he would give it full throttle and come charging around the corner. Picture a steam locomotive bearing down on you. That's how it felt to me. He could handle his chair well and he could barrel into you, using his metal foot rests as battering rams. It was no joke. We were at this for a couple hours at least. He was patient down there, like a crocodile.

I admire his determination; *now* I admire it. At the time, I felt persecuted. Why wouldn't he relent? He was determined to punish me, and to hold his ground. He was determined, I remember also, to beat his illness. He told me a couple times that he was "gonna beat this thing." His illness. You can't create the gene necessary for the protein necessary for the intracellular matrix necessary for proper functioning of muscles. You couldn't tell him that. You could have, and my dad probably did, but he wasn't listening.

He was determined, also, at the end of his life, when he was given a choice by the doctor to do a tracheotomy. He determined not to get one. He had been in and out of the hospital with pneumonia, and this time he was not coming out. He was in an iron lung, a great big yellow submarine-looking thing, with just his head poking out. And he was being fed through a tube. One of his great joys in life was food. And piña coladas. A piña colada is a sweet cocktail made with rum, cream of coconut, and pineapple juice, usually served either blended or shaken with ice. It may be garnished with a pineapple wedge or a maraschino cherry, or both.

So, he refused the trach. And gave the ok to pull the feeding tube. He asked for some morphine so he would be comfortable. And that was it.

Scene Two: Chase had a domestic side. He liked getting in his pajamas (I remember a blue pair with piping) and getting into bed and having a coke with crushed ice served with a straw and a bowl of popcorn. We liked to watch the Million Dollar Movie, which

was the late night movie in Houston. I think this was when movies like cost a million dollars to make. I would pull out the sofa bed in his room and we would have a sleepover. We did this a lot. A hundred times maybe before I got too old for it. I think it worked out to about once every weekend for several years. I would be there for companionship and to adjust his pillows, to situate his leg just so, and then, when that was wrong move it back this way and that way and this other way until finally I got it right. He would always thank me because when his leg wasn't in the right place it was very uncomfortable for him. He couldn't relax.

He liked to swim, or it was more floating; in the water he was weightless, and he had much more mobility. It was like he was an astronaut in space. Slow-mo freedom.

He had some moments of ease. But he also enjoyed even more being a bit rowdy, a little bit bad. He would come to my basketball games and when the other team had a free-throw right before they'd shoot, he'd shout: MISS IT!!!

Some people would look over at him, this chubby kid with round face and kinda greasy hair. Then he'd do it again. Because you get two freethrows usually.

MISS IT!!!!!!

He liked shocking me. He told me once how many of his nurses, his attendants that got him in and out of bed, and put him on the toilet and into the bath, and dressed him, he enjoyed telling me how many of them he convinced to have sex with him. It was 4. I remember all of them. Not their names anymore. They were with us for a year or two or three. Eventually they all moved on; usually they quit because they got tired of his being rude to them, "being nasty," my mother used to say. If she only knew how nasty.

They were all really kind, that's how I remember them, so I was shocked that they had sex with him, which at the time I thought was something not very nice. He shocked me again several years later when he told me (he had moved out of the house to his own apartment) that he regularly hired prostitutes. I didn't know what to think. We didn't like high-five or something like that. I probably just sat there and tried not to seem too uncomfortable. We were middle class. Prostitutes were not really a part of that picture. But he wasn't, if you think about it, really a part of that picture. Being middle class is about social mobility. You live in the future. You work for your future.

Like all hedonists, Chase liked telling jokes, and singing songs *a cappella*, but he often messed it up. And he would get really frustrated. And blink his eyes and sorta jerk his body back and if the parents weren't there drop the F-bomb. He'd spit it at you if you made him mad. He would actually literally spit at you sometimes. Which my parents came down hard on. Not very middle class to send a gobber at your little brother. But if he was mad, damn the torpedos, he would spit at you, or slam his chair against you, or if you were too quick, into the wall. And back it up and slam it again.

He wasn't going to hold anything back.