

# Stare at Me

How Being  
Blindsided  
Brings Life  
Into Focus

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with Michele Matrisciani

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## CHAPTER 5

# FA Night

**A**fter a long, hard-fought regular season, the championship game finally arrived. The St. Anna Tigers were undefeated, and we were up against the second-place Catholic Cathedral Bears, who were 16-1 (their only loss was to us). We were confident we could beat them again, given the strength of our team and our overall chemistry. We were playing like a well-oiled machine.

On that cold winter day, my dad, Sean, and I headed to the gym for the championship game. Ryan, who was away at college, called to wish us good luck. We got to the gym an hour before tipoff. I felt like a pro athlete wearing my dark-grey hoodie and baggy sweatpants over my uniform and snow boots. My game sneakers, Nike headband, Kobe Bryant sleeve, and a basketball filled my gym bag. I had on my headphones to listen to Lil Wayne's *Tha Carter III* to pump me up. I felt like The Man when we arrived at the gym. Our team was dialed in and didn't speak to anyone. We remained in the zone.

Tipoff came. We wanted so badly to win. So did the Bears. The game was competitive from the jump, and the score went back and forth. And I stayed on the bench. I had not seen a second of playing time. As the first half ended, I wanted to question why my dad hadn't put me in, but I managed to keep quiet. Sean had played well, yet I was frustrated. I figured since the game was close, I wouldn't play a lot, but I knew my dad would put me in at some point. He knew how much I wanted to play.

The second half started as intensely as the first, with both teams playing with purpose. The Bears took the lead, and with seventeen minutes remaining, we were down by one. I sat on the edge of the bench, just waiting for the signal to get on the court. With twelve minutes left, we regained the lead and were up by three. My blood started to boil.

*Maybe I won't play? Wait, that can't happen! That won't happen!*

With seven minutes left, we were up by five. I was still on the bench, keeping my seat warm. Then the two-minute warning buzzer rang. Sean and the others had taken control, and we were up by nine. We were going to win the championship. With so much breathing room, my dad finally walked back to where I sat, turned to me, and asked, "Joey, you want in?" I took a look at the other team's bench players checking into the game and was ashamed. Since I did not want to be associated with "lesser" players, I declined. I was hurt that my dad would even put me in this position.

*What did I do wrong? What was the point?*

We won by eight points. Or, I should say *my teammates* won by eight points. All of my best friends won that game without me. For the first time in my athletic career, I went an entire game without playing. I had gone from star athlete to benchwarmer in just two years, all while my fraternal twin brother kept climbing to become MVP of the game. My head was spinning as my teammates shook the other team's hands.

My confusion fueled my anger, and my anger led to deep sadness—sadness that my natural athletic ability had been lost, and to what, I had no idea. I used to kick ass framing the ball behind home plate, sneakily fooling the umps to get a called strike.

I could play stellar defense, going after guys double and triple my size in football and lacrosse. Now, when my brain told my arm to dribble the ball, nothing happened. My fancy footwork had been replaced by clumsiness and frequent tripping. My reflexes were in slow motion.

While the team cheered and danced around in the locker room, I began changing back into my winter clothes. I was upset that my dad had benched me and did not even offer an explanation. I could not handle seeing parents praise my teammates. I needed to leave the gym as fast as I could. I didn't want any obligatory congratulations hugs. I found my mom and she drove me home.

During the twenty-minute ride, I ranted to my mom about not being as good as everyone else anymore. She stayed patient and let me vent. Then, I did what I hated doing most: I cried—no, I *wailed* like a baby who'd lost his favorite wubba. My mom tried to calm me down, but I couldn't stop. I just needed to get home.

Immediately as the car stopped in our garage, I ran upstairs to my room and continued to cry for what seemed like hours, alone. I tried to cry silently when Sean and my dad got home, but they heard me anyway. I hated myself even more for crying then.

It got very late, but I was nowhere close to sleep. Apparently, neither was my father, who called me into our playroom and sat me down on the couch. He shut off the TV and put his right arm around my shoulders. He was having trouble looking me in the eye. I was ready to brush off his apology for not playing me while ignoring him as he told me how much he loved me and blah blah blah. But he didn't say he was sorry. Instead, he said: "Joey, I need to tell you something I should have told you a while ago. You have Friedreich's ataxia."

And just like that, my whole world came crashing down. I knew it was real, and I did not even question the horrific news. I had the same disease Kaela was battling. In a matter of minutes, I saw my entire life. I'd learned firsthand what was to come from watching Kaela struggle. I'd seen how this disease forced Kaela to stop dancing and playing sports. She started having trouble walking and needed someone to help her to do pretty much everything. All because of FA! She had to stop doing things she loved because her body wouldn't allow her to do them anymore. This was my future now.

At thirteen, I no longer felt invincible or that some good-old-fashioned hard work would solve my problems.

I bolted back to bed sobbing while my parents, Sean, and Kaela followed me in. They all cried with me, trying to assure me that life would be okay. But I was too scared to believe them. I didn't know what to think. The unknown was my new worst enemy. I cried myself to sleep, just so afraid. That day, that night, that moment, and those bone-chilling words have shaped my entire life. FA was a curveball, and in my mind, that meant it was lights out—game over.

When you're growing up, you might desire to be a famous movie star, walking down red carpets with paparazzi everywhere, or the next big musician with eight platinum records. You're living in a big mansion by the ocean somewhere on an exotic island with your beautiful spouse and three kids, whom you teach how to ride a bike, walk, and talk, and preach to about how great chocolate chip pancakes are. Once they grow up, they'll have kids of their own, making you a grandparent who will spoil them with love. Suddenly, I didn't know what to desire or what was realistic for me to anticipate.

## Stare at Me

I don't know if the mountain's altitude got to my brain, but things seemed to shift for me after that day. I saw everything more clearly.

I had become comfortable with my disease and comfortable with the special treatment it afforded me. People were kind to me, my professors praised me, and my peers would call me a “savage” or whatever for doing nothing extraordinary at all. Everyone was wicked friendly to me, but I knew after the climb that that would not help me.

On that sunny morning in May, my brothers didn't just carry me up Sleeping Giant. They showed me a better way to the top. It would require me not only to rely on others for help, but to dream big and push myself to get where I needed to go.

People knew me as the friendly boy on the scooter. It was time for me to show everyone I was more than just what their eyes could see. I wasn't just a friendly boy on a scooter but a young man who is bold, charismatic, and hardworking.

For years, people have stared at me—and it's not out of meanness. They're just curious about my scooter, my slurred speech, my inward-turning feet, and my “chicken legs.” But if people were going to stare, I wanted it to be for better reasons. I didn't want to be gawked at like a car wreck backing up the freeway.

It was time to give people something to *really* stare at—something big, something they wouldn't forget. So the new question I

asked myself was, *What would I need to do to keep people staring at me?*

To help everyone see past the scooter, I began taking on more responsibility. I moved into an off-campus, ADA-accessible SigEp house. I lived with Nanna, Mike and our brother Nick. Even though I had never lived with Nick, he meshed with our trio perfectly. Nick's lovability, loose hips on the dance floor, and desire to always go out of his way to help made him an amazing roommate and friend.

Living off campus might not seem like a big deal for an able-bodied person, but it was in my world. If I fell in my new bedroom or in the shower, I no longer had an RA or twenty floormates there to help. If I wanted dinner, I couldn't go to the cafeteria and grab pre-made food. I had to shop and prepare food on my own. And instead of waking up thirty minutes before class and scooting to my classroom with ten minutes to spare, I had to wake up two hours earlier to get ready, prepare food for the day, drive to campus, then race to class on bunny mode. It was challenging, but I needed this struggle.

Being a political science major, I figured getting some form of government experience would be good. So, I ran to be the president of the Class of 2017. Only members of my class were allowed to vote, and since I knew many students, I liked my chances. But my opponent already had experience as our class president, so he easily beat me. However, unbeknownst to me, if someone runs for president, they are automatically put on the ballot to become a class representative spot in QU's Student Government Association (SGA). Although I lost the class presidency, I was voted by the 1,800 members of my class to serve as one of eight Class of 2017 representatives. In that position, I worked with various SGA

members to address student needs and quality-of-life issues, like adding more food options in the cafeteria, more water stations in the dorms, and more parking spaces for commuters.

The entire student body elected SGA's Executive Board. It featured the president, vice president, vice president for finance, vice president for student experience, and vice president for public relations. These five people were in charge of SGA, and the rest of us followed their command with envy of their power and authority. They all received a stipend, and QU gave them offices on campus. In chess terms, I was an SGA pawn. The SGA president was the king. If an opponent takes the pawn down, it does not affect the game. But a king, queen, bishop, rook, or knight is tougher to knock down. Those positions matter, and I wanted to matter.

As my time as a class representative came to an end, my fraternity brother Jonny asked me to meet him in his office. He'd served on the SGA Executive Board that year and was running unopposed for president. Jonny, a native of Massachusetts with a thick Boston accent, was my "Big" in SigEp—an older brother chosen to be something of a personal mentor to me, on top of being my fraternity brother.

I saw him as a leader, someone I wanted to emulate. Due to his friendly personality and charm, he could have a great conversation with anyone on campus. When he called me to his office, I headed straight there on bunny mode.

Jonny told me he wanted to assemble an ideal Executive Board for the coming year. He asked me to join him as vice president for public relations. The significant duties were fostering a strong relationship between QU and the town QU was in, maintaining a strong image at QU and to QU administrators, and managing

an eight-member SGA Public Relations committee featuring representatives from each class. I immediately said yes to Jonny and entered the race against two strong opponents who were campaigning hard. After the entire student body voted, I found out I had won.

On the Executive Board, I now felt like a bishop on the chessboard. I had more authority and influence in the eyes of students, professors, and administrators at QU. I sat in on many meetings with QU administrators about how to better QU's campus, and I met with town officials. I also got to know more students around campus.

During the weekly SGA meetings, each Executive Board member had an opportunity to share updates. As president, Jonny led the meeting, while the four other Executive Board members sat at a table with him and faced the other thirty-seven SGA members.

Those meetings brought me back to my days as a catcher in Little League, looking out at the other players on the field. The experience reminded me of my sports days and the mindset I needed to push myself beyond my limits—Mamba Mentality.

With Jonny's term as president nearing its end, I knew it was time to show the real me, the real Joey.

Having FA has taught me not to squander my time. I try to live in the now. Announcing my candidacy for SGA president required I act now, worry later. I didn't think about how fatigued I became from keeping up with my duties as VP for Public Relations. I didn't think about how I often missed going to the gym for my daily exercise, or how I could barely stay alert without drinking multiple cups of iced coffee per day, or how I overextended myself at times. What would happen if I did win and become the face of the QU student body to every student, parent, alumnus, professor, administrator, and trustee?

No worrying and no whining. Just as if I were back on the court or on the field, I simply wanted to win.

My run for president was no different from how I'd played lacrosse. I was going up against a tough competitor and I needed to go all out. I had to frame pitches, just like in Little League. I held on to concrete causes and goals for the school, among them diversity and accessibility. I was the only person on campus in a scooter. The one student in a wheelchair was graduating. Nobody else knew the physical struggles of a disabled student the way I did. In no particular order, these were some of my complaints:

Too many inaccessible dorms with only steps for entry, forbidding me from visiting my friends.

Zero handicap-accessible parking spots in the sophomore parking lot.

Not being able to get on a shuttle bus.

Academic buildings without automatic doors.

Not knowing if I could get into the cafeteria.

*I could implement change.*

For my campaign, I leveraged my strong relationships within the Greek system and with administrators with whom I'd worked closely. I wanted to prove I could be president, that the shy kid who scooted around instead of walking was now scooting softly and carrying a big stick.

I ran for president as part of a trio with two of my best friends and fraternity brothers, Alec and George. Alec was running for vice president unopposed, and George was running for VP for finance. Unlike my previous campaign run, this one was exhausting both physically and mentally. Per SGA rules, you can only campaign a week before Election Day. Day after day, I went around campus with George, while Alec promoted our ticket from his computer.

We went to the gym, classrooms, and dorms talking with students, hearing out their concerns, and explaining how we would work to improve the school.

*“Hello! My name is Joey Mullaney, and I am running to be your next student body President! How can SGA help improve your college experience?”*

This question was my opening statement for each of the 600-plus conversations I had that week. I felt like a legit public servant, even ending meetings with hugs before heading to the next campaign post. At night, I focused on campaigning online by creating Instagram and Facebook posts about our ticket’s ideas and goals.

When you’re in a wheelchair or scooter, many people look at you with pity and sadness. They feel bad for you. They believe your life must be a hundred times harder because you’re physically disabled. They might even think you can’t do anything impactful because of your disability, or that you’re even afraid to go outside.

President Franklin D. Roosevelt famously said, “The only thing we have to fear is fear itself.” My fear forced me to stop playing sports in eighth grade. My fear made me stop going to the mall, movie theaters, or anywhere else in public growing up. Sean had to face my fear for me at the assembly as I hid; Petey had to save me from my fear and getting arrested at Rachel’s Sweet Sixteen; and Coach Kev had to pardon me from failing because I’d been too afraid to face my fear of public speaking. Even when I thought I’d gotten rid of my fear, my adversary, I was wrong. I’d only distracted myself from facing it head-on. My fear will only end if I stop it. I was in control now. I was ready to handle FA.

My running mates and I ran an excellent campaign. I was proud of myself for scooting way outside of my comfort zone. I didn’t let my fatigue stop me, I still found time to exercise, and I didn’t

get upset when I fell while transferring from my scooter to a toilet seat. Instead, I just stayed focused.

No matter the outcome, I'd been amazed by the feeling of seeing my peers stare at me during one of my many stump speeches around campus. The surprised looks on their faces told me they were thinking, *Wow! This kid is for real!*

Finally, Election Day came. I woke up that morning at six and immediately began campaigning online, using texts, social media, and email to tell people to vote. Alec continued our virtual campaign all day, while George and I spent the day continuing to talk with students and encourage them to vote. It almost felt as if my body forgot to get tired because I was continually going on adrenaline. When the polls closed at 8 p.m., the three of us sat together in the cafeteria—my first meal of the day—and waited for the phone call with the results.

At 8:14, I received a call from the man who'd motivated me to strive for greatness. Jonny said, "The results are in! Your opponent received 49.95 percent of the votes, and you received 50.39 percent of the votes. Congratulations, future Mr. Student Body President, you won! All three of you won!"

Here's what I learned about myself: I love hard work. It's a rush for me, and campaigning provided this rush and much more. But I only discovered these things because I had a challenger, and it wasn't my opponent. We all need challengers, even adversaries—any type of force that is trying to stop us, that wants to see us fail. But we don't fail. Instead, we shatter that glass ceiling with grit and hard work.

When I was running for SGA president, people looked past the "guy in the scooter." I didn't receive special treatment. Nobody went easy on me.

After I was announced the winner, I had to put my money where my mouth was. At least I had the summer break to get myself ready.

Senior year. Could time pass this quickly? It seriously felt like yesterday that I arrived on campus. Heading back to QU for my last year was bittersweet. I was excited to begin my presidency, but I couldn't believe it would be the last fall I'd return to campus. My first act as SGA President was to address the freshman class during Welcome Weekend on a stage with QU's executive president, executive vice president, dean of students, and chief marketing officer.

Many thoughts and memories rolled through my head about my freshman year, starting with leaving my twin, second-guessing my decision, learning self-discipline, being scared, falling off my scooter, becoming independent, having great experiences with friends, and rushing SigEp. Now, here I was. QU was my home away from home, and in many ways, I'd discovered my true self there.

I had gone from being petrified about addressing the student body at Lawrence Academy to becoming a pretty damn good speaker, and I had learned to love public speaking despite my physical speech issues. I worked on the Welcome Weekend speech over the summer, writing it twice. Through the process of revising, I developed my voice and my message.

Overlooking the sea of newcomers, some still as young as seventeen, I closed my remarks with:

Before I end, I acknowledge that you will receive a lot of advice in these next few days about what college will be like and how you need to approach these next four years. You've probably been receiving it all summer—from parents, siblings, aunts, uncles, just

about anyone who has college stories to share. You do not have to take my advice, because you may think that I do not know the answers since I am only a few years older. However, like your family and friends, I am only trying to help. Here are my three tips:

1. Embrace the change.
2. Step outside your comfort zone.
3. Tackle your fears head-on.