The Pain That Burns

Miles Ryan Fisher

According the McGill Pain Scale, what my best friend suffers from is some of the most excruciating pain one can experience.

Worse than unprepared childbirth.

Worse than amputation.

Worse than cancer.

It's a debilitating chronic pain called Complex Regional Pain Syndrome (CRPS)—formerly known as Reflex Sympathetic Dystrophy (RSD)—a condition in which the nervous system malfunctions and sends pain signals to the brain long after whatever injury precipitated it has healed. The pain grows disproportionate to that of the injury, making its sufferers writhe to the point that even a gentle touch is painful. In most cases, the pain remains localized, staying in the region of the body—usually a limb—where the injury occurred. The pain is so excruciating that some sufferers choose to have the affected limb amputated just to rid themselves of the pain. In my friend's case, however, it spread throughout his entire body to the point that it has reduced him to a 36-year-old invalid.

Justin and I met 33 years ago when we were just three years old. It was our first day of nursery school at Supplee Presbyterian Church in Maple Glen, a suburb of Philadelphia. On that day (from what we're told), I arrived first and wandered into the classroom, not knowing any of the kids already there. I looked back toward the entrance of the classroom and saw Justin, clinging to his mom, sobbing, begging her not to leave him alone. I walked up to him.

"Do you want to play?" I asked.

He turned and nodded, and just like that, Justin forgot his mom was even there. We went off to play, and from that day forward, were inseparable.

Just as we finished college in 2004, Justin began to regurgitate whatever he ate. He grew gaunt. Then he started throwing up even when he wasn't eating, and that led to the first time I saw him on a hospital bed. He lay there in Abington Memorial Hospital, the same place where I was born, vomiting nothing but the bile that remained in his stomach. The doctors couldn't determine why because they failed to do a routine test that would have detected the parasite in his intestine. Instead, they inserted a feeding tube directly into where the parasite dwelled.

It was that surgery that triggered a condition far worse than what Justin was already experiencing. The pain grew to be excruciating, a kind of pain that those with CRPS describe as "feeling like their bones are burning." The doctors became even more perplexed. They couldn't readily diagnose it because it was a time when few doctors knew about CRPS. To this day, doctors haven't determine just why this pain condition develops or just who will develop it. One doctor even told Justin it was psychological—the pain was all in his head. And if anything hurt him worse than the pain, it was being told that what he was experiencing wasn't real.

He underwent various treatments, though there was and still is no cure (and very little treatment) for CRPS. In the most radical, non-FDA approved treatment, he was flown down to Monterrey, Mexico, and put into a ketamine-induced coma, a procedure that lowers the body into a barely functional state and then raises it out so that its nervous system (hopefully) recalibrates. It helped Justin initially, but during recovery he contracted swine flu and the incapacitating pain returned.

Now, eleven years after the pain first developed, Justin relies on a daily diet of painkillers. He swallows a mixture of methadone and dilaudid that would kill a normal person. The medication barely gets him through the day as he lies there, confined to a hospital bed in the living room of his home in Fort Washington, Pennsylvania—the one I often visited when we were younger to play sports against his older brother and our other friends. But now, the only sports there are on television. Watching television is one of the few things he can do. He can't pick up a book; he can't use an iPad; he can't make a phone call. When I call him, his dad has to hold the phone up to his face so we can talk. When I email him, his mom has to read him my messages.

Surrounding him in his childhood living room are all kinds of sports memorabilia—an encased Lakers jersey signed by Shaquille O'Neal, a baseball signed by Ted Williams, and an signed Eagles jersey signed by Justin's favorite player when we were growing up: Randall Cunningham. I got it for him by contacting Randall, now a pastor in Las Vegas, and telling him about Justin's condition. It's one of the few things I've been able to do outside of visiting him.

Meanwhile, I'm here in Washington, D.C., where I've lived since graduating college. I remember when he visited me right after I first moved down. I'd joined an adult baseball team, and he came to my first game to watch from the bleachers with a bucket of beers. I didn't know a single player on my team and didn't play much of the game—getting just one at-bat. Afterward, Justin handed me a beer he'd saved, and we drank together as the field emptied. By the end of the season, I was hitting leadoff and had made friends with some teammates who remain close friends to this day, more than a decade later. But they've never met Justin.

I've played in hundreds of adult league baseball games since that first one, but Justin hasn't been to any of them. I've had girlfriends he's never met. I've gone on trips to places he's never been. I've even stood as best man at his brother's wedding and carried his grandmother's casket—both in his place. While I can set foot in his life, he can't set foot in mine.

Most times these thoughts don't disarm me—I've long grown hardened to them. But when they find me, they arrive in some quiet moment, some soft spot in my life when nobody else is around and a thought of him catches me off guard. I start to cry as if I've lost a friend—even though he's still alive.

I cry over what he's experiencing, and selfishly, I cry over what I'm experiencing, too—a life where the best friend who was always supposed to be there for you—to support you, to pick you up when you're down, to hand you that beer when you need it—isn't there. He's miles away, lying in a hospital bed in more pain, more anguish, more agony than I'll ever know. Yet here I am, wishing that *he* could be there for *me*.

Even though I've known him since we were three, I can't pretend to know how losing 12 years of his young life affects him, or how there's no foreseeable end to the constant pain he's enduring. We don't talk about that when I visit. Just like we don't talk about how it affects me. As pale in comparison as that may be, I know it would hurt him to hear words of how his pain affects me. And I know his mom would never read them to him.

What his mom will do is continue holding onto her wish that one day he and I will be sitting on a beach together—something calm and quiet after the pain he's experienced has stopped burning. Should that day come, I don't know exactly what we'll say to each other. Maybe we won't say anything. Maybe I'll simply hand him a beer, the one I've been saving for him.

And maybe he'll know to hand me one back.