

and its Discontents
Ch. 13-15

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How Tourette Syndrome
Made Me the Teacher
I Never Had

Now with a New Epilogue

BRAD COHEN WITH LISA WYSOCKY

Foreword by **Jim Eisenreich**, former professional baseball player with TS

Chapter 1

A “Playable Identity”

I grew up in St. Louis, Missouri, home of the Arch and home of Cardinals baseball. My parents, Norman and Ellen, divorced very early in my life—so early, in fact, that unlike many children, I was far too young to think that the divorce had anything to do with me. Of course it didn't. By the time I was old enough to even realize that my parents were divorced, that's just the way life was.

To say that I was a very active kid is a complete understatement. At the mall, my younger brother, Jeff, and I were the kids who tore through clothing racks and down the aisles, and generally wore our mother out with our boyhood energy. But the difference between Jeff and me was a question of intensity. Jeff, eighteen months younger, was a typical rambunctious boy—the kind who might be a pain to deal with sometimes, but who was otherwise like most boys.

And me? My energy levels were more manic. My fun seeking was much more frantic than Jeff's, and my excitability level was much higher. By the time I reached second grade, my relentless hyperactivity was understandably a huge concern at home. My mother realized that something was going on and that it was a disturbance deeper and stronger than anything behind Jeff's youthful outbursts.

Back then, Internet access was still a few years away, and there wasn't much information available to answer her questions—or silence her fears. At that time, social resources for conditions like mine were so few and far between that as my symptoms grew deeper, my mother and brother found themselves alone in the house with a virtual stranger. He looked like me, but he was entering all of our lives in staccato bursts of behavior that I couldn't predict, and over which I had very little control. I, like many people with Tourette syndrome, have a short attention span and some mild obsessive behaviors. (Many with Tourette syndrome also have attention deficit disorder, ADD; attention deficit hyperactivity disorder, ADHD; or obsessive-compulsive disorder, OCD.) And so along with the beginnings of facial twitches and rebellious behaviors came the attention span of a gnat.

We all stumbled along, hoping for the best.

My father, who was not a daily presence in our lives, paid just enough attention to my outbursts to dismiss me as an irritating kind of kid. This prevented him from asking himself some hard questions about what was going on. I know my emerging behaviors both embarrassed and disappointed him. I was a subpar version of that idealized firstborn son, the one whose fantasy image lurked in the back of his, and every father's, mind. The irritation that he felt toward me—and that sometimes turned to raging anger—prevented him from having to endure any intimacy with his baffling boy. He could always distance himself by falling back on the familiar pattern of being in a snit over my latest outburst.

Looking back from an adult perspective, I am sure my father also had some feelings of helplessness. Here he was, seeing us only on weekends and trying to establish a new kind of

workable relationship with his ex-wife. Some people just ignore what they don't understand and can't fix. Later, I found out that my dad was following advice he had received from several doctors. They told him that my problems were behavioral and that I needed more discipline. I think he has always regretted how he reacted, but, unfortunately, at that point in his life it was the only way my dad knew how to cope.

And this phase was only the lead-in to my problems. The real beginning was at summer camp, before starting the fourth grade. Each year Jeff and I spent at least a month at Camp Sabra, which was about two hours west of St. Louis, near Lake of the Ozarks. I loved it there because I was able to run and jump and swim off a lot of my excess energy without being yelled at. I loved the organized sports, the camaraderie with the other kids, the counselors—everything. But this year, I developed a strange new habit of clearing my throat every few seconds, all day long. Most of the time I had no awareness of doing it.

Naturally, the other kids noticed. But since no one—including my family and me—had ever heard of Tourette syndrome, nothing much was made of my little habit. Mostly the kids thought it was funny, even though as the season wore on, my frequent throat clearing became a near-constant grinding in the back of my throat.

During closing ceremonies at the end of the summer, my counselor gave me an improvised “Froggy Award” for having so amused everyone with my funny noises all season. I wasn't upset by the tongue-in-cheek award or by the hand-lettered paper certificate. Up to that point, my vocal tics had developed only to the extent of throat clearing and an accompanying assortment of odd grunts. I could usually get away with letting people assume I was some upstart kid who made funny little noises as a running joke—and I was happy to let them think so.

Inside, though, my strange behavior was so upsetting and confusing that I did my best not to deal with it at all. So, despite whatever implied mockery may have been behind the Froggy Award, I clearly remember stepping forward to accept it without feeling any awkwardness. In fact, I beamed like any class clown getting reinforcement for his antics. The award and the positive attention helped me to believe—for a little while—that I might be able to bury the weird little behaviors, or hide behind the appearance of an eccentric joker.

Sure, a reputation like that draws a lot of heat from authority figures, but an eccentric joker is an identity you can play when out in the world. People might regard you with annoyance, but they don't feel the need to stare. And when they do look at you, they don't see a freak, they see a playable identity—meaning that, for a little while, I was able to pull it off. Nothing wrong with me, folks—just a funny guy who likes to make funny noises, okay?

In the years since, people have asked if I was hurt by the implied ridicule of receiving such an award. But at that time, a source of wisdom deeper than I could understand was already guiding me to ignore any jabs and to choose instead to accept the element of honor that was there.

I can't take credit for that wise (or lucky) choice, but I've certainly learned how to employ it since. It's amazing to me, whether I'm considering my own life or someone else's, how often I see examples of people reacting with anger or pain to a personal slight without being able to realize that they are in a situation in which they have another choice: they can decide that the

comment or behavior they consider hurtful might also be legitimately classified as a flattering piece of attention.

No, it won't always work. I just know that my life and my career add up to concrete proof that it often can work. When we decide to experience someone's attention as a positive sign, that can lead to positive outcomes.

With summer over, the dreaded new school year began, with its endless hours of enforced quiet time and its low tolerance for funny, smart-mouthed guys like me who "insist on constantly drawing attention to themselves with subversive little sound effects." That's a direct quote from one of my former teachers.

Have I mentioned how much I hated school? I was not a good student then. I didn't have the attention span to stay quiet very long, so teachers were constantly criticizing me. And, as in the book *Lord of the Flies*, the kids in my school turned on the one child who was different from all the rest. They taunted me, beat me up when they could, and ignored me—when a simple, friendly smile would have gone a very long way.

And these were only the early days of the emerging symptoms. The intruder had been sleeping in the basement of my life, but it was waking up fast. Soon everything was going to be much worse.

On top of my emerging tics, we had recently moved and I was starting a new school, Green Trails Elementary. It was only about eight miles away from our old house, but it meant a new place with new kids and new teachers and no familiarity with anything at all. I was very stressed over both the move and the new school.

To compound these problems, in addition to clearing my throat I had also developed a habit of knocking my knee against the door of the car when I was a passenger. Of course that kind of behavior drove everyone nuts. Who could blame them? And when I insisted, "I can't help it," it's easy to see how people would wonder just what the heck I meant by that. Was I actually claiming that I "couldn't help" being an annoying jerk?

The knee-knocking-in-the-car behavior provoked my father to the point that he would lose his temper and actually hit me to make me stop. The shock of taking a slap, and the fear of getting another, was enough to halt my range of tics for a short while. But the problem was that the tics never stopped for long. Even when I knew I was going to get smacked for it, I found myself repeating the behavior. Remember, Tourette's includes uncontrollable neurological behaviors. Telling people with Tourette's to stop a behavior is like ordering someone with allergies not to sneeze.

And so the joker identity quickly became a lot less playable. No one was laughing anymore, particularly after I added yet a third tic to my repertoire, a piercing woop or "bark" that was to become my calling card. Imagine sitting in a classroom next to someone who, several times a minute, emits loud noises such as "RAH . . . rah . . . rah" or "wah . . . WAH." Throw an occasional "WOOP" in there and a continual set of facial spasms, and you are sitting next to me. At times my noises were much louder than they are now, and so during many of my school years I must have been nearly shouting.

The bark appeared to arrive on its own, fully formed as a tic. It seemed to me that one day I wasn't making that sound, and the next day I was. As with my throat clearing, I barked automatically and hardly gave it a thought. It played well enough around the house, but out in public, barking got me noticed. People's amusement quotient isn't at its best when they're confronted with a kid making loud sounds in public. After two or three good yelps in the wrong setting, I found it pretty hard to pass them off as being some sort of goofy sounds that I liked to make just for fun.

Additionally, I was running around like a maniac, so my mother took me to the doctor. He put me on Dexedrine, which was commonly prescribed at that time for ADD and ADHD. I was never diagnosed with ADD or ADHD, but stimulants such as Dexedrine reduced my hyperactivity. Over the next few years, as my behavior progressively worsened, my medication dosages became progressively higher. At the time both my mother and my doctor thought that was the correct treatment for my hyperactivity. Later we would learn it was not necessarily so.

My—and Jeff's—extraordinarily high activity level was one of the reasons for our move to the new house and school. Mom thought we all needed to have a fresh start, so she moved us to a new neighborhood that still had a number of Jewish families and was still reasonably close to a dynamic Jewish Community Center (JCC). My brother, Jeff, loved our new house, our new school, and the new kids to make friends with. Although Jeff is a year and a half younger than I, even at that early stage his greater social ability was a sign of the growing differences between us.

I found the move highly stressful. Adapting to foreign situations had become one of my weakest points. The out-of-control changes inside filled me with a strong distaste for changes elsewhere in my life. Additionally, I kept my fears bottled up inside, which added to my stress and to my tics. I didn't like to share my feelings, and the eventual emotional toll this took was huge. Also, as I wasn't yet able to predict how bad my tics might become in any given situation, going out in public became an increasingly dicey proposition.

With social disaster always lurking outside the door, I craved routine in every other area of my life. The safe predictability of home helped me retain some small feeling of control. But even inside our new home I was not fully comfortable.

For example, my mother's bedroom was on the first floor, while the rooms Jeff and I occupied were upstairs. In our old home, all the bedrooms had been together on the second floor. That difference alone set off my anxiety. I refused to sleep in my room upstairs. Instead, I dragged my pillow and bedspread downstairs and spent every night on the couch in our wood-paneled den, using the glow of the television to ease my fear of the dark. It became important to me to have a night-light of some kind, since darkness promoted uncertainty and uncertainty equaled anxiety. Slowly, my daily and nightly routines became more and more focused on clinging to the familiar and avoiding the unpredictable.

My behavior created a vaguely ominous backdrop. If anyone other than our mother—any child-care professional, for instance—was charged with taking care of us for very long, he or she soon quit. It usually took only a single evening to scare off a baby-sitter. My mother could barely

control Jeff's hyperactive behavior, and she accepted the fact that sometimes no one could control mine. My behavior had reached the point that some people, baby-sitters included, found it frightening.

I must admit that at least some of our behavior with the baby-sitters was intentional. Like children being taught by a substitute teacher, we gave our sitters a hard time just because we could. Jeff and I were mischievous boys who enjoyed the chaos we were causing. It was fun to tip over furniture and throw things around the room! But I admit that it often got out of control. Neither of us knew where to draw the line. Our hyper states were fueled by increasing activity, and I can easily see how Jeff and I together were a bit much.

My grandmother Dorothy provided Mom's only respite. She was my mother's mother, recently widowed, and willing to employ her free time in helping Mom out, even on short notice. We called her Dodo, and we adored her. Sometimes Jeff and I spent the night in her little apartment. She was completely accepting of my energy level and my funny noises, even if her downstairs neighbor was not. Every once in a while, he banged on the air-conditioner vent with a broom to get us to quiet down. Regrettably, tics do not care about the time of day or night, or whether the neighbors are angry about the noise.

My childhood was not all doom and gloom, however. A real ray of sunshine came into my life when Mom and Dad chipped in and bought me a terrific green bicycle. I discovered a new source of freedom outdoors—a boy on a bike can speed all over the neighborhood, making all the noises he wants, and no one thinks a thing of it! When I was riding my bike, that terrible, growing conspicuousness that was beginning to dog me everywhere dissolved in the wind and the motion and the exertion of riding.

I named my bike the Green Dragon, and to me its speed was unmatched. I challenged other kids to race, and I usually won. Luckily, the Green Dragon was as resilient as it was fast. It survived two major accidents, one when I propelled it head-on into a brick wall and another when I flipped over a sewage drain and had to be taken to the hospital by ambulance. I got a concussion, but the Green Dragon was unscathed.

The Green Dragon was more than an extension of me. It was a symbol of my physical freedom; it was my disguise. When I was riding the Green Dragon, my condition was invisible. That bike was my most loyal friend—and a real protector. On the Green Dragon, I forgot about my tics and all the problems they were causing for me and my family. Speeding up and down the hills around our neighborhood with the wind in my face, I was like any normal kid. I wished those hills would go on forever.

Since I was in constant motion all day long, Mom signed Jeff and me up for after-school programs at the local JCC. Her thoughts about an active center and organized activities proved to be right. Jeff and I participated in all kinds of sports there, depending on the season: baseball, floor hockey, basketball, soccer. We both loved the place; we could stay all weekend and be thoroughly entertained. I even loved keeping score for the adult intramural basketball games . . . everyone yells at ball games.

Optimistic people often tried to reassure Mom that both my brother and I were nothing more than healthy, active boys. And with Jeff, it was true. But it was also true that my behavior was becoming progressively worse, and Mom was having a harder time keeping me in line.

It wasn't just a matter of little behavioral tics that I couldn't suppress; I was having a harder time keeping myself "in line" all the way around. Fear of my mother's displeasure wasn't nearly as bad as the fear that I was losing the ability to control all aspects of my behavior. Whatever the cause, it was becoming extraordinarily difficult for me to get along with other people. Most adults saw me as an overly rebellious, willful kid. But I struggled with the creeping suspicion that my willpower, the basic ability to control myself, was dissolving within me. My behavior had become so bad it terrified even me.

My poor brother was the one most often in my vicinity, so I frequently picked fights with him. Jeff was more forgiving and understanding than I could expect anyone else to be, but he had his limits, too. Years later, Jeff told me that he often purposely egged me on. He wasn't proud of that fact, as even then he knew I couldn't help my behavior. Some of it, he said, was peer pressure—he was, after all, the brother of the weird kid. But some of it was just the fact that we were brothers and very close in age.

That second fact holds a perverse truth: those fights actually helped me. Much of what I was going through was learning different ways to cope with the strange tics, and the fights helped me in my struggle to appear normal. They shifted attention away from my tics and back onto me. Normal kids get into fights, too.

Mom still hoped most of my tics and hyperactivity would calm down as we continued throughout that school year to settle into our new surroundings. She also thought Jeff and I needed more time with our father. Right after we had moved, he had relocated out of state, and so we now saw him only on holidays and would see him for a longer time in the summer. But Mom's idea about me needing more contact with my father didn't prove to be correct. The tics got worse when he was around.

I now see the increase in my tics, particularly during visits to Dad's place, as being a direct result of the anxiety that was produced by being around a man who did not know how to deal with the rapidly changing behavior of his son. The absence of an accurate diagnosis was causing years of frustration and the development of parenting habits that were counterproductive.

In those days, what my dad was to me was a large male with an unpredictable temperament. In fairness, what a "son figure" I must have presented to him! Each visit was odder than the last. While my tics progressed at a safe distance from him, he only saw the development of my symptoms as if they were stills from a movie. And those scenes weren't long enough to help him find a way to cope.

At least when we were separated by hundreds of miles, Dad could be the fond absentee father. We had great phone conversations every Sunday morning. But on those increasingly rare occasions when I was actually in his presence, he was confronted with a normal-looking boy who possessed some inexplicable need to make himself look and sound ridiculous.

I understood that I was supposed to feel some level of instinctive fondness for my dad and a connection with him as my father, but his positive attention had become virtually impossible to obtain. I always had a guilty sense of relief when it was time to leave his house and go home. But the relief was mixed because I didn't really know if I wanted to go. Sometimes I would cry on the plane on the way home because I was sad to be leaving him, but at the same time it was very nice to get back to my daily routine.

At the age of seven, when we were still living in our old house, I had been assigned a “big brother” (in a Jewish mentoring program similar to Big Brothers Big Sisters) and had the great good fortune to be paired with an astoundingly stable, committed volunteer named Steve Mathes. Steve was just twenty-four, and already married and the father of a baby boy, but he still found time to take the big-brother role seriously. We got together every other weekend. We went to Cardinals baseball games, and once we went to see the Harlem Globetrotters. Steve took me to the zoo with his family and had me over for dinner on Friday nights. His wife, Julie, loved to cook and made solid, basic meals such as meatloaf with pumpkin pie for dessert. It was the kind of comfort food that I wasn't used to at home, as Mom was usually too frazzled by us to cook big meals. Sometimes Steve and Julie invited me to sleep over, and I was always glad to stay. On Saturday mornings, we'd head to the local donut shop. I loved and thrived on the regularity and consistency of my times with Steve. Even after my family moved farther away, Steve and I continued getting together often.

Steve has said that rather than adopting the usual one-on-one role that big-brother programs usually encourage, he instinctively included me as part of his family. Steve somehow knew that the little things, such as watching a grown man shave (as I never had seen my dad doing) were very important to me. He never tried to be a dad, but he helped me see what being a man was all about.

To me, Steve represented all the good in the world because he had very high expectations for everyone, including himself, while at the same time he played fair and behaved like a winner. He saw the best in me when others didn't. As time went on, the unselfish way that Steve and Julie invited me into their family showed me that even though I was different, I could still find acceptance in a normal and safe place. I took great pride in being a part of Steve's family, and we've remained a part of each other's families since then. Steve has been to all my graduations, and his son—who was just one year old when Steve and I first met—is now twenty-three and lives in Atlanta, having attended Emory University. To this day, Steve Mathes remains my strongest male role model.

Excerpt from *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had* by Brad Cohen with Lisa Wysocky

To learn more about *Front of the Class: How Tourette Syndrome Made Me the Teacher I Never Had* please visit Brad's website at www.ClassPerformance.com. On the site you can read Brad's blog, sign up for his newsletter or buy the book.