Exorcising ghosts

by

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A personal meditation on the nature of a neurological disorder.

There are three hundred students in this auditorium, and I can only hear one. He is sitting in the corner by the stage, lost in a sea of freshman bobbing in and out of their seats, waves of them crashing onto my ears. The professor adjusts his mic; his drawling voice comes over the speakers, asking for quiet. The ocean settles down. The professor starts to speak.

And the boy in the corner cries out. The noise sounds like the honk of a seagull, an inhuman *EE-YAW*. There is momentary panic in the audience. Everybody's eyes turn to the corner. Murmurs. The professor loses his composure for a second, and then continues.

He cries out again. It sounds like someone clasped a giant wrench around his stomach and twisted, forcing a screech out of his throat. Now concern mixes with confusion. Whispers. *Is he alright?*

By the third or fourth cry, there is no more confusion or concern. There is just a horrible tension, an awkwardness that gnaws at you like a rat on your brainstem. Everyone handles it differently. Some keep looking at him, as if suddenly he'll realize what he's doing and stop. Others have decided the most polite thing to do is glue their eyes forward, as if passing a shrieking beggar on the street. Still others keep shifting in their seats, stealing glances at their neighbors, unsure what to do.

It's like the nightmare where you show up to high school naked, only worse, because everyone's had that dream, everyone understands that, but nobody understands this.

I do.

The class ends. I collapse with relief, and melt into the exiting crowd.

I was diagnosed with Tourette's in 7th grade, but I'd been twitching since kindergarten. My first tic – that's the technical term – was eye-blinking. I don't mean your run-of-the-mill heavy blinking, like from a valley girl with fake eyelashes. I mean like a camera shutter, open-shut-open-shut-open-shut.

"It was really hard to watch," my mom says. My mom is a short Argentinean woman. While she talks, she is spreading sautéed vegetables over a breadcrumb stuffing in the hardwood kitchen of my house in New Jersey. It smells of mushrooms. "We were alarmed. Umm… But you seemed happy."

The eye-blinking continued for a few months. Nobody in my kindergarten class seemed to notice. "I don't think socially it was a problem," my mom says. "The other kids were oblivious."

Then the eye-blinking morphed into lip-licking. That's what tics do, they morph. One wanes and the next waxes. It's a relief when it happens, because it gives one of your body parts a rest. Your eyelids get to pass the torch off to the next runner. Not that lip-licking was much better. In my kindergarten photo, the skin between my lip and my nose is red-raw.

But there's that moment when you realize you don't have to blink anymore, and for a minute, you can relax.

After kindergarten, I switched from public school to Montessori school. Tile became carpet; multiplication tables became singing circles.

And lip-licking became sleeve-chewing. My shirts from those days are ragged, like they've been fed to a junkyard dog. My first grade teacher tried to get me to stop. "It was one of her missions in life," my mom says. The teacher punished me constantly, made me roll up my sleeves every few minutes. Eventually I did stop, but not because of her; sleeve-chewing morphed into elbow-jerking, toe-rubbing, and wrist-turning.

By third grade, I was having more than one tic simultaneously. I'd be sitting on the blue carpet of our classroom, sunlight streaming through the big glass windows, the teacher talking about *The Giver* – and I would jerk my right elbow out and quickly pull it back in. A few seconds later, again. A moment to breathe, and then I would circle my left wrist until it cracked. Then I would pull my right shoulder up in a shrug and release it. Then my right elbow again. Elbow. Wrist. Toe. Wrist. Elbow. Thumb. Elbow. Shoulder. Elbow.

What made me tic? Think back to a time when you had an itch that you couldn't scratch. Maybe the itch was on your knee, but you were getting an MRI scan and couldn't move. Or maybe the itch was on your right forearm, but your left hand was entwined with someone else's and you didn't want to let go.

At first, the itch is mild, no more than a tingle. But it builds. Ten seconds. The itch is stronger, God it would feel good to scratch it right now, but no, you're strong, you can resist. Thirty seconds. The itch is wild, the urge to scratch all you can think about.

A minute. You can't take it anymore; the urge is just unbearable; your eyes start to water. Screw the MRI, screw the girl, screw the consequences, goddamnit *I just need to scratch*. And you give in.

That is what it feels like to tic. But instead of an urge to scratch, it's an urge to lift up your arm, or to crack your wrist, or to twist your neck. Asking someone to stop is like asking them to not scratch.

This was my life, every minute of every day. It's like a god in your head you have to feed or else he'll drive you to insanity. All you can do is hand him one morsel at a time, and hope that, for a few moments, he'll leave you alone.

My parents didn't do anything about my tics. "We didn't know that that was a *disorder*," says my dad. He is seated next to me in the kitchen, arm on windowsill, wearing sweatpants and an old t-shirt. "We didn't know that that was related to anything."

According to the latest 'Diagnostic and Statistical Manual of Mental Disorders' (DSM V), Tourette syndrome is a neurodevelopmental motor disorder characterized by "sudden, rapid, recurrent, nonrhythmic motor movements or vocalizations" – tics. It was first documented by Monsieur Gilles de la Tourette, a bearded neurologist who described nine patients with curious symptoms. There was a boy in a Parisian ward who flailed compulsively; the Marquise de Dampierre, a noblewoman who started yelling obscenities at age seven; and the Jumping Frenchmen of Maine, a group of remote lumberjacks who jumped when startled. His insight was that all the cases were related, and in 1885 he published a seminal article on a “nerve disorder characterized by motor incoordination.” The disorder was later redubbed Tourette syndrome, and was codified as a modern diagnosis in 1980 by the third version of the DSM. Once considered a bizarre condition reserved for strange lumbermen, Tourette’s is now recognized in about .6 to .8 percent of the population. It has spawned an active body of research, much of it funded by a nationwide advocacy organization called the Tourette Syndrome Association (TSA).

TSA’s website lists many fun facts about Tourette’s. Tics can be motor (eye-blinking, elbow-flailing) or vocal (seagull-honking). They are “involuntary,” but are usually preceded by “premonitory urges,” like the kind I described. Most cases of Tourette’s are mild. They all start in childhood, and most fade by adulthood. Most don’t involve screaming curse words. As the site puts it, “Most people with Tourette’s will lead productive lives. There are no barriers to achievement in their personal and professional lives.”

Much is known about the disease on the surface. But when you reach a section of the website requiring more scientific depth, the quotes become laughable. “What causes TS? It’s complicated and no one knows for sure, but scientists think that TS is caused by problems in one or more parts of the brain.” “Is TS inherited? Yes. We think that there are genes which are responsible for TS, but so far we have not found the gene or genes which cause TS. We also know that environmental and situation factors can have a big effect... It is best to think about both genes and environmental factors as important to the cause of TS.”

The actual scientific literature is more informative. The neurological cause of the disease, according to the leading hypothesis, is some kind of imbalance in dopamine pathways, such as too many of a certain type of dopamine receptor. And studies on twins and families have indeed suggested that the disease has a genetic component. If one of your parents has Tourette's, there's a 10 percent chance you have it. If your identical twin has it, there's a 50 to 70 percent chance you have it. There has been significant work done to identify the genes responsible; one paper cited twelve candidate genes and chromosomal regions. Environmental factors have also been explored, such as "perinatal insults, exposure to androgens and psychologic stress, as well as post-infectious autoimmune mechanisms." In other words, fetal boo-boos, male hormones, worrying, and strep throat all increase your likelihood of having Tourette's.

Still, most authors acknowledge how much uncertainty remains. Each paper seems to start with a disclaimer. "Genetic studies have not detected unequivocal disturbances in metabolic pathways in TS patients." "Major gaps remain in our knowledge of the etiology of tics." "The pathological processes of tics remain unclear."

And the landscape is even foggier when it comes to a cure. There are two major classes of treatment for Tourette's: drugs and therapy. Drugs are usually tried first. Consistent with the hypothesis that Tourette's is caused by overactive dopamine receptors, the most commonly prescribed drugs are antidopamine pills – called, quite scarily, "antipsychotics". In clinical experience and small-scale studies, these drugs have been effective. But rigorous evidence for them is lacking. A recent review found only three high-quality studies comparing a popular antipsychotic to a placebo – and only one of those three studies showed any results. The story is similar for other drugs. Though they have been in use for decades and have yielded promising results, most of them have never been thoroughly vetted.

Therapeutic options seem equally promising. In 2008, researchers at UCLA and the University of Wisconsin published a 132-page book on a behavioral therapy treatment for tic disorders. The critical component of the treatment is “habit-reversal training,” in which patients learn to maintain awareness of their premonitory urges and introduce responses that “compete” with the tics. For example, if the tic is jerking out your elbow, you might learn to cross your arms instead. The therapy has already successfully reduced tic severity in two large, controlled studies, and offers an appealing alternative to drug treatments.

The fact that behavioral therapy successfully treats Tourette’s raises a pivotal question, one which is often asked about neurological disorders. Is Tourette’s really neurological? Is it really a disorder?

TSA certainly thinks it is, and has worked tirelessly to convey that image to the general public. The organization rightly believes that if people understand tics are involuntary, then people will be more tolerant of the disorder.

Few dispute TSA’s claim that tics are involuntary. Why would anyone jerk their elbow out a hundred times a day if they didn’t have to? But there are different shades of the word ‘involuntary’. If tics are unstoppable in the same way heartbeats are unstoppable – if my elbow kept flailing out without my permission – it would be difficult to see

Tourette's as anything but a bona fide disease, a misfiring of neural circuitry, as real as cancer or herpes. But if tics are like itches, the answer is not so obvious.

My experience is that tics are like itches, and there is evidence that my experience is the common one. Most patients report premonitory urges before a tic, and a momentary sense of relief afterward. Most patients can suppress tics for a short period of time, but are soon overwhelmed by an irresistible urge and give in. Most patients aren't puppets; they are agents, consciously performing the motions that their hungry god has urged them to perform.

So the question is: Where does that god come from? I can only speak from my own experience, and that maelstrom began in fifth grade.

"Fifth grade? It was horrible." My mom has finished with the stuffing – it is roasting in a slow-cooker on the granite countertop. She is now sitting across the kitchen table from me, looking me right in the eye. "Fifth grade was when you started having real problems."

The summer before fifth grade, I went to a summer camp called Rambling Pines. There were a bunch of older kids, sixth graders. One afternoon I was sitting with them at a picnic table. One of them made a joke, said that I didn't pee standing up. I didn't get it.

"It's cause you're a girl," one said. "Girls don't pee standing up."

They all laughed. I pretended to laugh too.

Montessori school wasn't much better. I was chubby, and the kids who I had once loved started to say things like: "God said *let there be light*, and all Adam had to do was move out of the way." My mom was a teacher at the school, and she had to work for a few hours after classes let out, so I went to the afterschool program. It was run by a Belgian named Mrs. Bergmann, who could have been a distant cousin of Hitler. I hated her and the program. I used to sneak into the hallway, find my mom's office, and pace in front of her door until she came out and I could beg her to take me home.

My parents have a different set of memories. They remember my meltdowns in the car, how I would scream and kick and throw my body against the car door. My mom would hold my arms down, and I would start smashing my head against the seat, over and over until she would give me what I wanted. We were once out to a sushi dinner, and I remember thinking *I have to get out of here*. I didn't know why, but I told my parents *We have to go*, and then I panicked and my grounding vanished and I was falling and crying and throwing my head against the wall and begging them please, please, let's go.

This was when my parents took me to a therapist. The therapist was a hotshot – she had a parenting book out. She would only see you for ten sessions, because if you weren't cured by then, you were hopeless. I sat in her beige office and told her how I had a list of faults in myself that I wanted to fix; then I told her all the ways I had dreamed of killing one of my teachers. She diagnosed me with anxiety and depression, and I ended up on Prozac.

But there was some research coming out at the time that Prozac wasn't safe for kids. "I was putting you to bed one night," my mom tells me. "You were very agitated, unhappy and crying. I'm like *Adam what's wrong*, and you said, *I don't know, I don't know*… So I asked you, *Do you want to hurt yourself? YES, I WANT TO HURT MYSELF.*" She took me off Prozac the next day, and these thoughts subsided. Therapy was over.

But the whole time, my tics got worse. I started teeth-grinding, neck-twisting, finger-cracking. At this point, I was ticking nonstop. In class; at dinner; in bed; in front of the TV. Neck. Elbow. Finger. Teeth. Teeth. Neck.

In 6th grade, I switched back to public school. My parents talk about this time with relief. I made new friends; my tantrums disappeared. Amazingly, even though I was a fat, twitching geek from another school, kids were nice to me. Middle school is like Russian roulette: survival is luck of the draw. My chamber happened to be empty. Even though some people poked fun at my tics, I was never seriously bullied. I had a good math teacher, a cute babysitter, and a new dog. On the surface, at least, my life was fine.

But my tics were worse than ever. This was the first time my parents threw out the word "Tourette's". They decided to take me to a man named Dr. Wollock, who was part of an experimental group in a nearby hospital. I remember the dark wood paneling in his office, which I sat against while I took diagnostic surveys. Endless doctors, endless questionnaires.

Eventually we got the results. They were hazy. Wollock couldn't give me a diagnosis yet, because at that point all my tics had been motor. The Tourette's diagnosis – and its social disasters – only officially starts when tics become vocal.

People can forgive motor tics. A flailing arm or a blinking eye is strange, but easy to ignore. Vocal tics are what make people whisper when you pass them in the hallway. Vocal tics are what made everyone stare at the honking kid in the corner of my college class.

His name is Mark. Some time after that class, I contacted him on Facebook and asked if I could interview him.

I met him in the first-floor lounge of his dorm. I was nervous. I expected to be meeting a basket case, a recluse crippled by self-consciousness, the kind of kid who hates his reflection, who sits alone in the dark on Friday nights twitching.

I was right on one count. He twitched. A lot. His tics were even worse in person. He was sitting in a green chair across a small table from me, and he was never in the same position twice. His legs were moving constantly, left calf across right thigh, foot bouncing incessantly, left leg out, kicking the table, back in, right across left. Same with his head. He would arch it back, then throw it forward against his knee, then back against the wall. Every time he arched his head back he would honk. Occasionally he would yell *WHY*, or other words that sounded like Chinese. This was Tourette's at its worst. It was frightening to watch, as if there were a ghost in Mark that he couldn't exorcise.

But all of my other predictions were dead wrong. Mark was open and self-aware. He was an artist; he painted surrealist representations of photographs. He was a rapper; he had a SoundCloud with recordings of his original songs. He was writing an autobiography, called "Born Without Wings", about his family and his experience with Tourette's. He wanted to be a doctor, because it was a kind doctor who first helped him accept his condition, who told him "the world could be a safe place." His stated goal is "to leave a footprint on the world."

Mark has led an extraordinarily difficult life. His parents got divorced when he was in kindergarten. The experience was scarring; he spends the first five chapters of his autobiography on how his parents fought for years, how his mom tried to pit him against his dad, how his step-mom read his private diary.

In first grade, his mom took him to an elementary school in China, where their family was originally from. The school was totalitarian. Mark tells the story of a kid who stayed up past curfew one night. He was caught, and forced to stand against a wall, knees perfectly straight, all night.

That year, Mark started having a curious urge to roll his eyes.

Three years later, his biological mom died in the hospital. His tics have been growing stronger ever since.

But he has friends. His close friends from middle school accepted him when his tics got worse in high school. When he got to college, his freshman floor took him in with open arms. His biggest complaint: “The bathrooms were disgusting.”

He even has a girlfriend. This last one blew me away. “Has Tourette’s made it difficult to meet girls?” I asked him.

“As long as I’m confident, most don’t mind,” he said. “She actually asked *me* out.”

How has Mark survived, thrived even, with a condition that makes it difficult to hold a conversation? Part of it has been through the kindness of others. His favorite memory of college is of the first day of classes. “I went up to this chemistry professor… I had to explain to him my condition, that I mean no disrespect.” His tics subside as he talks. “(The professor) put his hands on my shoulders, and said: *Don’t worry about it. Everyone has their struggles*.”

He sits perfectly still. “That made my whole life,” he says.

But Mark’s success also comes from his strength. In the introduction to “Born Without Wings”, he writes:

“i trod along the path others blow dust over.
i walk through the forest they skim across.
i swim the waters they easily circle around.
yet i still go on.”

Mark told me that he would not wish his condition on anyone else. He speaks of dark times, when he wants to rid himself of his burden.

But in many ways, Mark is a success story. As TSA's website puts it, he will lead a "productive life."

I am happy for Mark. But I am also terrified by him, because that was inches away from being me.

One day in 7th grade, I started coughing. A tickle in my throat grew to an unbearable swell and I coughed. Then it happened again. And again. The tickle would not go away, and I hacked through the whole class.

The next week, I started honking.

A guidance counselor called my mom. *Your child cannot be in class. He's honking.* My mom organized a conference with the guidance counselor and one of my teachers, strode into the meeting, and broke down hysterically. When she got home, she pulled me out of school.

We immediately went to Dr. Wollock. Same wood paneling, but no surveys this time. Now that I had a vocal tic, the diagnosis was clear. Gilles de la Tourette could have written his thesis on me.

So Wollock put me on drugs. Clonodine, Guanfacine, Clonazepam, and Topamax. Two ADHD pills, two seizure pills. An experimental cocktail. Topamax was the strongest. Its Wikipedia page lists 267 side effects, including formication, the sensation of small insects crawling under your skin. My mom spent two weeks emailing Dr. Wollock every time I ticked, coughed, breathed, or shit; he emailed back with how to properly adjust the doses.

“Wollock was my god,” my mom says. “I was so depressed. I talked to (my friend) about it, because I was working with her at the time, and I remember telling her about it and crying… I was worried about the drugs you were on, but I wanted you symptom-free, I wanted you to be able to be a normal kid.”

“We were desperate,” says my dad. If the drugs didn’t work, “there was no other option.”

The drugs worked. In two weeks, I stopped honking, and I was able to go back to school.

But my motor tics never stopped. Elbow. Elbow. Ankle. Ring finger. Elbow.

My childhood came to a head that summer, at Napoleon’s tomb. We were in Paris on a family vacation. We had met up with some old family friends who lived in Paris, the Loesche’s. They had a son named Tomas. We had been friends many years ago, but I was anxious about seeing him again.

We were strolling through the streets when I started feeling tightness in my chest. I had had asthma for years, so when I told my dad about the tightness, he gave me a worried look. He told me to say something if it got any worse.

We reached the tomb. It was a massive marble building. I remember the gravity of the coffin in the center, how the pillars seemed to orbit around it.

At this point, I was having a full-on asthma attack. My parents called the French 9-1-1. I sat on the white steps of the tomb, next to the armored statues, waiting for an ambulance. The sky was Simpsons-blue.

I remember the emergency room. Empty. Dimly lit. Elmo poster on the wall. The doctor was kind and spoke English. He checked my lungs, gave me a breathing test, and went over to my parents.

"He said, *His lungs are fine*," my mom recalls. "We didn't know what was going on. Then he started asking us questions. *Did he have some kind of – did something happen? Did you have a fight?*"

"We were like, *Why are you asking us these questions?*" She pauses. "He said, *This kid is having a panic attack. This is a panic attack.*"

At first my parents didn't believe him. They wanted to call my allergist at home, get his opinion. They wanted to blow the doctor off as some "crazy French guy."

"But he really impressed me," my mom says. "He was so kind to us, remember? He really impressed me as somebody with a soul."

In this way, Mark and I are similar: A kind doctor saved our lives. Because that was the moment when my parents put it all together. It was the first time they realized that my problems might be psychological, not physical. If stress could give me an asthma attack, couldn't it cause me to twitch?

In hindsight, it seems obvious. My tics started when I started kindergarten, when I started spending long hours away from home. They intensified when I started having social problems in the horrible fifth grade. They got worse when I was taking tests, got better when I was immersed in some kind of game. My fifth grade therapist had even diagnosed me with anxiety.

"But we were looking for a diagnosis we could fix," said my mom. "Because, it was actually harder, I think – it would have been harder for us to realize it was anxiety… Cause here, at home, you seemed very – you loved doing projects and the stuff you did… You know, you don't see your kids that way."

But after Paris, they started to. When my asthma acted up or my tics got bad, they started asking me how I felt, what was going on, was there anything worrying me. They did breathing exercises with me, helped me to relax. "For the first time," my mom says, "we started talking to you."

One afternoon, later that summer, my mom was fiddling through our medicine cabinet, picking up pill bottles, figuring out what drugs I needed refills on. I was standing behind her. I made an announcement: *I'm going off these meds*. My mom twirled around. *Are* *you sure, your tics might come back* – but I was adamant. So my mom called Dr. Wollock, and in two weeks, I was down from four pills a day to zero.

I am not the first person to claim that stress plays a role in mental illness. Most psychiatric researchers follow a ‘stress-diathesis’ model, which states that mental illnesses are the product of both natural predispositions and stressful life events which ‘activate’ those dispositions. Not all children with unhappy childhoods develop Tourette’s; not all children with dysfunctional dopamine systems develop Tourette’s either. You need both.

But the Tourette’s literature has largely shied away from the ‘stress’ side of the model. A paper in 2004 lamented the “surprising lack of research on the role of stress in tic disorders.” A 2010 review dedicated an entire section to neurophysiology, but only a paragraph or two to stress. There are still only a handful of studies on the subject.

This is despite the fact that the surface-level description of Tourette’s bears the unmistakable fingerprint of anxiety. Like my own, most tics appear at school age – a frightening period for a child. They peak in adolescence, perhaps the most stressful time in anyone’s life. They usually fade as adolescence fades. They get worse under duress and better with a calming task. And the most successful treatment for Tourette’s, the 132-page book on behavioral therapy, explicitly includes anxiety modification techniques, such as “relaxation training” and school interventions to help the child avoid stressful situations.

Yet most people are resistant to the idea that stress plays a role. Mark is a clear-as-day example. His tics started after his parents' horrible divorce and a mortifying year of elementary school. They got worse after the traumatic experience of his mother's death. But he doesn't think stress has had a large influence on his Tourette's. "Maybe trauma exacerbated it," he said. "Maybe it would have gone away otherwise." But in his eyes, and in the eyes of most others, the disorder is still fundamentally biological.

Even the researchers who developed the behavioral therapy are cautious. They boldly claim a "reconceptualization" of Tourette's, but they immediately follow with a concession that their research "does not imply that tics have a purely psychological etiology or that patients can suppress tics by force of will." They continue weakly: "Rather, our study lends clinical support to advances in basic science that emphasize the role of (neurological) circuitry on motor function and habit formation."

They are right to be cautious. Neurological dysfunction and the research on it are undeniably important. Recognizing that patients cannot just snap out of Tourette's is a necessary step toward destigmatization of the disease.

But that doesn't mean patients are puppets, or that they should just submit to their hungry god. Many people are going down a path of powerlessness and interminable medication. I think there is another way.

The day my Tourette's stopped was sunny. It was the same summer, after I went off the drugs. I was sitting on the beige leather sofa in my living room, ticking like a madman. Elbow. Neck. Elbow. Elbow.

My dad sat down next to me. He put his arm around me, and pulled me under his shoulder. He held me tight. He asked me the question that sits in the gut of anyone who's ever seen someone with Tourette's. *Adam, you really can't stop this?* I kept twitching under his arm and said no, I can't, I have no way of stopping. *I'm holding you; you can't stop this? I don't believe you can't stop this.* I can't, I've tried resisting, I can't.

The way I was talking reminded him of when my mom had tried to quit smoking, how impossible it was for her to resist a cigarette. He thought of a story my mom had told. In one of her attempts to quit, she had gone to a hypnotist. The hypnotist told her to put a rubber band on her wrist, and snap it any time she wanted a cigarette. Hard, so it would hurt.

So my dad took his arm off me, got up from the couch, and brought me a rubber band. Big. He put it on my wrist and told me what the hypnotist had told my mom.

I went downstairs to a room I called my cave. The indoor light was dim, but sun streamed through the unblinded windows. I sat in my black chair, staring at the pale blue wall, and I snapped. And snapped. And snapped.

And my tics slowed down.

It might have been the rubber band itself, training me like you would train a dog. Or maybe I was just old enough, and getting to that age where my Tourette's would fade naturally.

But what I felt was a long-lost sense of agency. Not agency to resist the urges once they were upon me, but to calm them, to hold back the anxiety like an operator at a floodgate. For so long, I had felt like a pebble in a river. That stupid little rubber on my wrist made me feel so powerful, powerful enough to build a dam.

I sprinted upstairs to tell my parents. I couldn't stop grinning. For hours I kept snapping myself, but eventually I took off the rubber band and practiced just raising that floodgate, calming my mind. A few hours later, I could hold off a tic for minutes. By the end of the day, I could soothe an urge.

By the end of the week, I could sit still.

It felt like I'd been dragging myself up a mountain, ragged and exhausted for my whole life. But suddenly I had reached the top. I could lie in the grass. I could rest. I could join my friends, who had been up there the whole time.

They don't appreciate the view.

My Tourette's is and always has been a channeling of anxiety. When I can control the anxiety, I can control the tics. Perhaps my experience is unique. Perhaps I was misdiagnosed. But I was practically a textbook case, and what the complicated drug cocktails couldn't do, a rubber band did.

Today, sitting in my kitchen that smells of mushrooms, I can control my tics for as long as I want. It took time; for months, I had to practice sitting still, every moment of every day. It takes energy; a small corner of my mind is always on guard, like a levee holding back the surges of stress. I still flail my elbow occasionally; when I write, I still crack my finger joints.

But you'd have to be paying attention to notice.

Tourette's is a disease that consumes you. You either deal with it or die. Mark dealt with it by embracing it, by channeling it into his creativity and his writing. It has defined his purpose, his identity, his career.

But for me the defining moment came when a college friend asked me why I jerked my arm out occasionally.

I smiled at him and shrugged. "I'm just a little twitchy," I said.