

Tic, Tic, Boom: Growing Up With Tourette Syndrome

By [Everyday Health Guest Contributor](#)

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When I was 6 years old, I developed a lasting cough that quickly gained a lot of attention. It wasn't an explosive hack, but a quiet reminder to everyone in the room that I needed to clear my throat. Apparently I coughed all the time. I didn't really notice it, but others did. Eventually people began making endearing jokes like "I knew you came in because I heard you cough!" or "I heard someone cough today and thought it was you!"

I knew those comments weren't meant to be harmful, but they still irritated me. But then again, I was easily irritated. My socks needed to be just right. I would stop my work in kindergarten to fidget with them until they felt right on my toes. If someone bumped my left shoulder, I would need to bump the other one. If I stubbed my left toe, I would hurl my right one into the concrete. Certain sensations and sounds would send me into a silent battle with my obsessive need to counter the sensory input with some other motion or noise. I didn't understand or even take time to question what was happening because to me my actions were normal.

Coughing, Twitching, Ticking

These emerging signs of OCD only increased in severity. Soon, they began to manifest in the form of vocal and motor tics which weren't as tame as the cough. My eye constantly twitched. Once, in middle school, the crease next to my eyelid began to bleed from the constant blinking. I locked myself in my room and focused on finding a way to stop it...maybe I could convince my brain to want to twitch the other eye?

I learned in my teens that I had Tourette Syndrome (TS). I don't remember where I first learned the term. I think I had heard about the disorder and decided that, yes, that is what I had been experiencing. I had never been to a physician regarding my tics, and everyone in my household basically ignored the fact that I had tics all together. Even when I couldn't stop shrieking or jerking my head before bed, the most acknowledgment my tics earned was an offer of a scented candle to help me relax. It may sound strange, but the way my family treated or didn't treat, my tics made me feel very comfortable and unashamed.

Despite feeling comfortable and accepted at home, being out in public presenting an entirely different story. I tried desperately to stifle sounds, and disguise my sudden movements. As a child and teenager, I lacked the ability or confidence to answer those two ever-looming questions: "What are you doing?" and "Can you please stop that?" Anyone with TS will tell you: "It's annoying me more than it's annoying you." Understanding and basic education can go a long way when it comes to understanding someone with TS.

Later I would learn that my disorder was protected under the Americans with Disabilities Act, as well as a possible 504 plan at public schools, which could afford me extra times on tests. I could have used the extra time, as sometimes my OCD made simple writing a challenge, as I would need to scribble in all four corners before I could write the words I wanted to write. Such silent battles with myself could take up to 5 minutes or longer.

However, I never needed to solicit any of these protections. I was lucky to have friends that would defend me when teachers accused me for being loud or distracting. I was lucky to have sisters who stood up for me if someone at a restaurant made a comment. I was lucky to have, for the most part, understanding family and extended family members.

What TS Is Like for Me

I did, as an adult, overcome any worry about what strangers might think about me. It would take a pretty strong insult to get me upset, and an even stronger one to shake my self-confidence. Now, tics don't annoy me because of the attention they attract. Tics annoy me because of the mental and physical exhaustion they cause. Sometimes I really just don't feel like getting out of bed and rolling my already sore shoulder ten times in a row before I can brush my teeth. It just adds to the stress of the daily grind. But we all have struggles, and we are all forced to do things we aren't very keen on doing. My struggle today happens to be with my left arm.

Tourette Syndrome causes a constant struggle between my brain and my body. Having a tic is like blinking, breathing, or itching a scratch. I do consciously control the movements I make but, just like blinking, I can't stave off completing the action for long. Blinking isn't so inconvenient, so there's really no reason to want to stop blinking. But when instead of blinking, I'm faced with squeaking, shaking, or punching my own stomach, I have quite the motivation for doing my best to suppress my tics. However, it isn't that easy. Performing a tic can consume all of my mental attention and push me to my limits. Even when I have a chance to lay down, they can still fight me until I finally fall asleep.

I'm faced with performing a routine of actions – turning my neck, shaking my head, screaming, bending my back, shaking my shoulder, clicking my jaw – in the right order. If I don't complete the series right the first time, if my scream wasn't loud enough, if I didn't lift my arm high enough, then I have to do it again. Your conversation will have to wait, finishing this test question will have to wait, sometimes I have to put breathing on hold until my compulsions satisfy my brain. I've chipped teeth from biting down on glasses – a tic I would later learn is very common among people with TS. I was 16 and out with friends when it first happened. I was confused and shocked. I resorted to spitting out the fragment of my tooth, throwing it away, and pretending nothing ever happened. Later, when I was alone, I ran to the bathroom to make sure the chip wasn't visible when I smiled.

Living with TS Now

As a preteen, I learned that is it common for tics to peak in severity during adolescence, and then disappear. However, this hasn't been the case for me. Even today, when I ride in cars, I roll my shoulder every time I pass a telephone pole. I straighten and contort my back before sitting down.

When I was in college, I decided to meet up with a group of people with TS. It was the first time that I had ever met or seen anyone else dealing with the same thing I was dealing with. The experience was life changing and I now feel less alone, and much more at ease. I'm now even an employee of Tourette Syndrome Association-NYC, where I get to help connect people with TS. TEAM TSA walks are a fantastic way to foster these experiences.

When I was 22, I consulted a neurologist for the first time in my life. Tics come and go in waves. For six days – or six months – they may be more frequent than usual, and then their severity may phase out. During one particularly harsh “wave,” I became worried because I had never had my tics interrupt my life so severely before. My body was sore and I found myself overly distracted at work – too focused on suppressing or performing tics. I learned that treatment options were mostly in the form of medication. I knew that (for now) medication was not for me. Eventually the “wave” waned, as I knew it would, leaving me less anxious and very relieved.

Living with TS teaches you quite a bit. Above all, it teaches you to respect your own needs. If I know my tics are getting bad, I've learned to stop what I'm doing instead of further exasperating myself. It teaches you to defend yourself and handle challenging social situations (or confrontations) with ease. I'm slowing learning which sounds and sensations trigger me.

All in all, my tics are manageable. They have changed my life, the way I live, and who I am; but they have never, ever, significantly limited my opportunities or hindered me. Having this disorder has made me a more understanding, accepting, and respectful person.

Sofia Desenberg is the administrative assistant at the New York City Chapter of Tourette Syndrome Association. To find more information about TS and TS Awareness, or to participate in a Team TSA walk near you, please visit tsa-nyc.org. You can contact Sofia directly on [LinkedIn](#).

If you live in the greater New York City area please contact the chapter at Chapter@tsa-nyc.org or call 646-395-0162