

For women, Tourette's syndrome means added burdens, and also rewards

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Sara Henya's art is her music, and her instrument is the harp. She makes playing look easy, effortless. Her fingers move like cascading water: fluid, graceful, sure.

But when her fingers are still, well, that's a different story. Her brain barks orders her body is all but helpless to ignore. She may hit herself in the face or on the chest. Maybe she will need to hit her elbows hard against the back of a chair. And then there are the sounds. They erupt out of her.

Profanities. Loud, unwilling. Yet those guttural sounds are as much a part of her as the golden tones she coaxes from her harp.

Henya, a resident of Northeast Philadelphia, is part of a small, largely understudied sisterhood. She is a woman with Tourette's syndrome.

"It's kind of precious to me," said Henya, 24. "If I had to pick whether I would keep it or get rid of it, I would keep it because I feel like my perspective on the world and who I am and how I treat other people is different than it would have been if I didn't have it."

Defined as a [neurodevelopmental disorder](#) characterized by involuntary, often repetitive movements and vocalizations called tics, Tourette's is estimated to affect 1 in every 162 children in the U.S., according to research.

But the U.S. Centers for Disease Control and Prevention has reported that as few as half of the children with Tourette's are formally diagnosed.

As with autism and ADHD, males are far more likely to have Tourette's than females—about four times more likely.

But Anthony Rostain, a Penn Medicine and Children's Hospital of Philadelphia psychiatrist and member of the Tourette Association of America's medical advisory board, says he believes that the social burden of Tourette's is particularly heavy for women.

"They're not supposed to be in any way socially unacceptable," Rostain said. "They have to look good, act right. They have to be perfect in many ways."

Some people such as Henya have the more extreme, stereotypical form of Tourette's. Coprolalia, [vocal tics](#) that manifest in cursing, occurs in only about 10% of Tourette's cases. Many others' tics are more subtle, even if they are chronic and pervasive. Tics are also unpredictable, shape-shifting over time. Tourette's has no cure, and there is no medication that works for everyone.

Some people can learn to somewhat control their tics at least briefly, but it is often uncomfortable, even painful to hide them. Highly focused activities, such as playing an instrument or sports, may have the effect of suppressing tics. Athletes with Tourette's include British soccer star David Beckham and former Philadelphia Phillie Phanatic Jim Eisenreich, who started a foundation for children with the disorder.

Tourette's diagnosis rates may be especially low in girls and women, in part because clinicians just aren't used to looking for it. Nearly 90% of the people with Tourette's have at least one other mental, development or behavioral disorder, according to the CDC, so those may be missed, too.

"If you're not looking for tics and you miss them, you're also not looking for OCD to occur," said Carol Mathews, director of the University of Florida's Center for OCD, Anxiety and Related Disorders. "You're not looking for anxiety. You're not looking for mood disorders. And those are things that often don't come to our attention because kids keep them inside."

Many experts say tics in either sex often peak in puberty and may level out or even lessen with adulthood.

However, Barbara Coffey, professor of psychiatry at the University of Miami's Miller School of Medicine and director of the university health system's Tics, OCD and Related Problems Program, said she has seen the opposite in some of her female patients.

"Certainly, some of the most severely afflicted middle-age patients I've seen with Tourette's have been women," she said.

Regardless of age, there is often a sense of relief or at least affirmation to be able to name one's differences.

Michael Rubenstein, a Penn Medicine neurologist who treats adults with Tourette's as well as youngsters at Children's Hospital of Philadelphia, was in [medical school](#) when a pediatric neurologist he was working with surprised him one day by asking, "So how long have you had Tourette's syndrome?"

"It was like a light went on," said Rubenstein, whose daughter also has Tourette's. "I was always a fidgety kid. I made it through school, but I clearly had issues that, had I known what this was, I could have done some therapy and I could have probably done a lot better in school."

Rubenstein's patients have benefited from cognitive behavioral therapy or medication. Armed with a diagnosis, some seek accommodations in school, such as more time to take tests or taking exams in a separate room so they need not stifle their tics or worry about interrupting others.

Rostain recalled one patient, a dental student, who spent her whole childhood trying to hide her Tourette's.

"Her parents were so upset, and she became so ashamed of it because they thought it would mean that she wasn't going to be able to find a good husband or have a good life, be a good mother because of her

imperfections," Rostain said.

When she started taking her tests in a separate room to keep from distracting others, it eased some of her stress and she did reach her goal of becoming a dentist.

"But she felt like she was being viewed as somehow a leper by people who didn't understand," Rostain said. "So she had to do a lot of educating the people."

Other women with Tourette's have taken on that role—or had it thrust upon them.

Billie Eilish, the 17-year-old singer/songwriter sensation, opened up about her Tourette's on Instagram several months ago after videos of her tics began circulating on the Internet. "...These compilations y'all been making of my tics are low-key funny even when y'all make fun of them. ... I know you're all confused ... so just to let ya know its tourette's," she wrote.

Last year, the Tourette Association of America conducted a survey about the impact of Tourette's and other tic disorders.

Nearly 44% of adults surveyed said the disorder prevented them from forming meaningful friendships or romantic relationships. Almost 77% of adults and 83% of children believed that Tourette's negatively impacted their school experience or education. About two-thirds of adults and youngsters said they felt discriminated against in school or work. Fifty-one percent of adults and 32% of children said they have considered suicide or self-harming behaviors.

Such organizations as the New Jersey Center for Tourette Syndrome and the Pennsylvania Tourette Syndrome Alliance, as well as the Tourette

Association of America, all endeavor to educate people about the disorder, including recruiting young members to talk about Tourette's at schools and other groups.

There are also such activities as Camp Twitch and Shout in Georgia and the Tim Howard Leadership Academy in New Jersey where youngsters with the disorder can enjoy the freedom to be themselves, tics and all. For many young females, meeting others in their situation can be life-changing.

Shayn Pulley, 28, is a non-binary person assigned the gender female at birth. A "late bloomer," Pulley had Tourette's erupt violently only about a decade ago. In one early tic episode, Pulley screamed for an hour straight.

"When it first got really bad for me, I didn't want to leave the house. I didn't want to go to karate. I didn't want to do any of the things I was doing," the Norristown resident said. "I didn't know how to explain what was going on with me. I was scared, and I was scared of how people would view me."

The youth camp and academy changed that for Pulley, who has served as a counselor and coach.

"Being in a space where tics were normal and not weird, I could just feel comfortable in my own skin," Pulley said, "and even flattered because people are like, 'Oh my God, I love your tics' to each other."

Carolyn Baldwin of Mantua, Gloucester County, has become a Tourette's activist. She doesn't have the disorder herself but all three of her children do.

All three, she said, have learned to be open about their Tourette's.

"You have to demystify it," Baldwin said. "They have to explain what it is, or otherwise they are targets."

When Anna, her oldest, was 12, she wanted to give a presentation to her class. Baldwin was worried for her.

"She said, 'No, I'm doing it,'" Baldwin recalled. "She said, 'Mom, if I'm standing there ticcing and I don't say anything, I'm the weird the girl in the corner. But if I tell them what it is, and they make fun of me, then they're just idiots.'"

Sara Henya has her brushes with bullies of all ages, including the teacher in a religious program that would giggle whenever she ticced.

But she did make friends at school, summer camp and science fiction conventions, and she does Tourette's outreach. Her husband doesn't have Tourette's but he finds her some of her tics endearing. "He thinks it's cute."

Henya said she's not sure whether she wants to have children. Tourette's runs in families. She said she wouldn't wish the syndrome on someone else, but if she had a Tourette's child, she'd know how to help her.

She offered this advice to parents of children with Tourette's:

"It's not your job to be afraid for your kid. Be as supportive as you can. You've got to be brave for them because they're going to be scared. They're working their whole body.

"Do as much research as you can, but stay brave, because they're going to be great. This doesn't stop you from having a good life."

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