

Truth about Tourettes - Not What you think

By Bruce Holtgren | Enquirer Staff Writer

It's impossible to navigate through popular culture without having heard about Tourette's syndrome. And why not? It's not exactly your ordinary medical affliction. Unfortunately, for most people, Tourette's is equated with its rarest symptom: involuntary outbursts of cursing and other inappropriate language.

You probably would be surprised to know that only about 10 to 15 percent of people with Tourette's have "that cursing thing," the peculiar urge that is known as coprolalia. I, too, used to think Tourette's was synonymous with swearing. Had I known the truth, I might have been diagnosed decades earlier.

Those who do exhibit coprolalia and other pronounced symptoms certainly deserve much more respect and compassion than they get. More broadly, everyone with Tourette's needs better public understanding, and especially an end to the stigma that surrounds this sometimes bizarre disorder.

Tourette's, a genetic affliction, is characterized by two or more "motor tics" - involuntary physical movements such as facial grimaces or moving the head, neck or limbs in odd ways - and at least one vocal tic, which is usually little more than humming, grunting or whistling. Onset usually comes by mid-childhood, with severity of tics most frequently seen by age 10 or 12. In the majority of cases, tics then gradually diminish to little or nothing by

Information and resources

I Have Tourette's But Tourette's Doesn't Have Me - An Emmy Award-winning HBO documentary in which children talk about the difficulties and misunderstandings surrounding having Tourette's. To order, go to www.tsa-usa.org price is \$14.95 or lower for TSA members or those buying in bulk.

tourettenowwhat.tripod.com Tourette Syndrome - Now What? Web site offers positive, accurate, current information on Tourette's, especially designed for parents just learning their children have TS. Lively message boards of mostly moms of kids with Tourette's.

www.tourettesyndrome.net Tourette Syndrome "Plus" site examines Tourette's alongside what are called "co-morbid" conditions that often occur with it. These can include ADHD, obsessive-compulsive disorder and learning disabilities.

en.wikipedia.org/wiki/Tourettes- The Wikipedia article on Tourette's is thorough, accurate and well-documented.

Myths and facts

Tourette's syndrome is mainly "that cursing thing."

False Eight to nine people out of 10 who have Tourette's don't have cases pronounced enough to include the most extreme vocal tics, called coprolalia.

People with Tourette's can stop ticking if they really want to.

Partly true People with mild cases can hold off ticking for a while, but must eventually tic later to compensate. People with the most severe cases can't avoid ticking for more than a few minutes or even a

adulthood. The course of each case is as unique as each individual; there is no such thing as a "typical" case of Tourette's.

A freak-show image

As medical problems go, Tourette's is, except in the most severe cases, about the most minor imaginable thing to have. It's never fatal, and very rarely a disability. Indeed, countless people live their whole lives without realizing they have the disorder. Countless others know they have it but don't bother with treatment or even getting a diagnosis because they can live with the tics more readily than bothering with highly imperfect medications and their side effects.

It is a cruel coincidence that tics so often peak just as children are entering their middle school years. We all remember how crucial it is to fit in at that age, and having a noticeable case of Tourette's can be a recipe for social disaster.

Public understanding of Tourette's and accommodations for schoolchildren who have it are slowly improving. There's still a long way to go; the freak-show image, unfortunately, still prevails overwhelmingly.

The blame for the warped perceptions lies overwhelmingly with the video media - the Internet, movies and TV. If you search for "Tourette" on Google or YouTube, you'll get a gazillion hits that almost invariably show the most outrageously extreme examples of motor and vocal tics. Television, with notable exceptions such as Oprah, has sensationalized Tourette's so badly, for so long, that it seems beyond hope that most people will ever know the more prosaic truth.

Give the kids a break

Fascination with the most lurid aspect of anything is just human nature. At some point, though, we can and should grow up and do better.

One of the best simple overviews yet of Tourette's came out in a 2005 HBO documentary, "I Have Tourette's But Tourette's Doesn't Have Me." It won an Emmy for outstanding children's

few seconds. In all cases, tics wax and wane over time.

Medications can cure Tourette's.

False There is no cure, but some medications can ease symptoms in some people.

People with Tourette's face a bleak long-term prognosis that includes a life of being shunned and even institutionalized.

False Virtually everyone with Tourette's is normal in every other way and can look forward to ordinary, productive lives.

programming, and for good reason: The kids in it talk poignantly about how painful it is not only to have such an often annoying affliction, but how badly people misunderstand it. These children offer some of the most thoughtful and eloquent observations I've seen about not just Tourette's, but basic respect for others.

And it's mainly kids who have Tourette's who are most in need of a break. For almost all the rest of us, it's a harmless nothing burger of a condition. It's certainly not the main thing about me, and it shouldn't be for anyone else either.

A friend once told me that one of the most profoundly wonderful things one human can do for another is to understand. In a world so desperately lacking understanding in so many other areas, I'm adding this small voice toward better public understanding of what Tourette's syndrome is - or, at the very least, what it is not.

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