

A PARENT'S AND EDUCATOR'S GUIDE TO IDENTIFYING THE SYMPTOMS OF TOURETTE SYNDROME

Tourette Syndrome (TS) is a neurobiological disorder characterized by tics— involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly. With a mere 200,000 reported cases of Tourette Syndrome (TS) in the United States, there is often the perception that TS is a rare disorder. While the numbers may not be alarming, there are certainly a large number of unreported and unrecognized cases of TS. Such unreported cases have a major impact on those who are affected by TS symptoms and those of its co-morbid conditions such as Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder and Anxiety Disorder.

Diagnosing TS

To more fully understand and recognize TS, it helps to start by taking a look at the diagnostic criteria. There are no medical tests used to identify TS. Diagnosis is made entirely by observing symptoms and evaluating a person's history.

The current DSMMD definition of TS is:

1. The person experiences both multiple motor and one or more vocal tics. These do not have to present themselves concurrently.
2. The tics occur many times a day, nearly every day, or intermittently throughout a period of more than 1 year without a tic free period of more than 3 months.
3. The symptoms cause marked distress or significant impairment in social, occupational, or other important areas of functioning.
4. The person experiences onset before age 18.
5. The tics are not as a result of a substance or a general medical condition.

Oftentimes, Psychiatrists or Neurologists that diagnose TS will also look to see if any of the co-morbid conditions are present and whether or not there is a family history of tics.

The diagnostic criteria are actually quite simple, yet it is common to hear the same story from parents and teachers of long-drawn-out histories of missed and delayed diagnoses. Medical professionals often admit that they are not taught about TS in their schooling and as is true with the general population, there is simply a large amount of misunderstanding about what TS actually is and looks like. This misunderstanding stems, in large part, from too much misinformation and the very incomplete, stereotypical version of TS portrayed on TV and in movies.

Frequent Problems in Identifying TS

One of the problems that parents and educators often have with identifying symptoms of TS is that symptoms change in number, frequency, type and severity. Symptoms can even entirely disappear for weeks or months at a time. TS symptoms are also often confused with symptoms of something else. For example, it is not unusual for the parents of a child with common facial tics, such as sniffing, nose scrunching, eye blinking and eye rolling to spend years taking the child to see allergists and eye doctors to uncover the cause of the symptoms. In many cases, the child actually does suffer from allergies or have impaired vision, further masking TS as the root cause of such tics. Thus, a simple and common tic results in missed or delayed diagnoses, with treatment not matching, or only partially matching, the cause.

There is also the issue of differentiating TS from other tic disorders, which may only include either motor or verbal tics and occur for shorter periods of time. These are typically referred to as transient tic disorders. The co-morbid conditions that are often experienced with TS only add to the confusion. Children with ADHD can have verbal or motor tics and exhibit behaviors similar to children with TS. And while that does not mean these children have TS, research shows that 65% of people with TS also have ADHD. In those cases, correct diagnoses can be critical, especially since medications for ADHD often cause or increase tics as a side effect.

Child with undiagnosed TS sometimes continue to present with symptoms until another symptom shows up that causes distress or the current symptoms simply don't go away. When the child is finally seen by a doctor familiar with TS, a diagnosis is often easily made, but time has passed and treatment has been delayed. With a better understanding of what to look for, both parents and educators can steer children with TS symptoms towards a quicker diagnoses and earlier interventions during often critical times in the child's education.

Who Gets TS and What Does it Look Like?

In identifying a person as having TS, parents and educators should keep in mind that TS is an equal opportunity disorder affecting people of all ethnic groups, professions and social statuses. Males are affected 3 to 4 times more often than females. Symptoms of TS can be mild or extreme, and are typically seen in 3 areas: motor tics, vocal tics and behavioral manifestations.

Tics often start in the face or head and are typically physical manifestations of something else. This is why we often see a sniffing or nose-twitching tic that develops after a child has a cold or suffers from allergies. The difference with TS from transient tic disorders, however, is that the tic doesn't go or stay away and will occur in both a motor and vocal form. Motor tics can be simple and easily recognized as tics (head shaking, eye rolling, neck stretching and shoulder shrugging), but many people are not aware of, and therefore do not recognize,

complex motor tics. These tics can involve the whole body and have multiple separate movements. They can be repetitive and have a compulsive quality. They are often mistaken as behavioral actions or compulsions and can be hard to distinguish from either. Actions such as hopping, skipping, excessively going over and changing written school work, and paper tearing will often get a child in trouble in the school setting long before they are identified as complex motor tics. Many people with TS also report having urges to perform motor activities that can result in touching things or people, or moving objects. Again, these actions often appear very behavioral, but are not commonly thought of as tics—resulting in delayed or misdiagnoses.

Vocal tics often occur with motor tics and do not need to be word vocalizations. Very common vocal tics are sniffing, throat clearing and grunting. These may or may not be commonly recognized as tics. More complex vocal tics range from repeating words or phrases to coprolalia, the involuntary uttering of obscene words. While coprolalia is most often stereotypically associated as a symptom of TS, it is an uncommon vocal tic and only affects about 10% of TS individuals.

Individuals with TS will sometimes imitate what they have just seen or heard and often can describe triggers that prompt their tics (such as seeing or hearing someone else tic or someone coughing in a certain way). Tics generally occur in bouts and their frequency can vary tremendously over short and long periods of time. Some people with TS can temporarily hold back tics for short periods of time, but typically this is just delaying their appearance and causing a decent amount of effort and restraint on their part. The best example of this is when parents describe the familiar occurrence of taking their child to the doctor because they are ticcing and then the child does not tic during the visit. Often, that same child will tic the entire car ride home.

Some children will not tic as much—or at all—at school when they are around their friends and peers. Holding back tics can cause distraction and inattention for the child, as he is focusing on not ticcing instead of what he is supposed to be learning. Other children with TS who tic freely in school settings—often because they cannot stop—are either more stressed at school or are comfortable enough to not worry about it. Although also distracting to the student, those that tic as needed at school are simply doing what their bodies have to do and these tics are best simply ignored whenever possible.

Along those same lines, children with TS will often tic in very different degrees at home and at school. This makes the identifying of symptoms that much more important, since it may only be a teacher or a parent who is seeing the child's symptoms. Teachers shouldn't assume symptoms they observe at school are also being seen at home and vice versa. This emphasizes the importance of communication between school personnel and parents when symptoms are noticed so that their source can be identified.

Although there is certainly a very physical aspect of TS, individuals with TS are often much more affected by the social isolation, academic struggles, and embarrassment the symptoms cause. While the symptoms can appear in almost any form and intensity and cannot all be listed, identifying specific symptoms is not nearly as important as recognizing that the individual is displaying actions he/she cannot control. The involuntary nature of TS symptoms is the most devastating and important part of the disorder. With even a small increase in the understanding and identification of the symptoms of TS, children with symptoms can be directed to the proper clinicians for evaluations, diagnosis, and treatment and receive help much earlier than is the current norm.

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