

TOURETTE SYNDROME – MORE THAN JUST A TIC DISORDER

Understanding TS to Advocate For Your Child

Tourette Syndrome (TS) is an extremely complex genetic neuro-behavioral disorder. Advocating for children with TS can be a difficult task. To be successful, it is important to have a solid understanding of the disorder as well as its impact on your child.

TS is primarily a tic disorder. To be diagnosed, a person must have both vocal and motor tics occurring for over a year (can be intermittently), with an onset before the age of 18. In most cases, TS is formally diagnosed by a neurologist or psychiatrist. Contrary to what is often portrayed on television and in movies, very few people with TS have coprolalia (the uncontrolled yelling of obscenities). Most motor tics are recognizable as tics: head shaking, twitching, shoulder shrugging, or eye rolling. Complex motor tics, however, can be difficult to distinguish from problem behaviors and are often interpreted as such, especially in a school, work or social setting. Examples might be tearing paper, poking, kissing, licking, jumping and obscene gestures. Vocal tics do not need to be actual word verbalizations and more often present as throat clearing, coughing, sniffing and humming. The physical aspect of this combination of tics can certainly interfere with your child's daily experience at school, but the social and emotional impact is often just as great, if not more profound. Feelings of social isolation, anxiety, rejection and a lack of self-esteem, combined with the constant fear of being punished by adults for uncontrollable actions is clearly not a productive or healthy way to get through a school day.

Although tics will wax and wane (appear and disappear) for various periods of time throughout the year, this unfortunately serves to reinforce the incorrect belief that people with TS can control their tics. While some students may be able to resist the urge to tic sometimes, this is only delaying the inevitable and the tics will still come out at some point. The effort and concentration it takes to resist ticing is extremely taxing and requires focus. This effort often interferes with the ability to concentrate on and follow school activities, whether listening to a teacher or working on a project. Because TS is a medical condition and the student cannot control the tics, the student should never be told not to tic. Later in this article, I will describe some APPROPRIATE ways to respond to or assist a student with tics, but reprimands or punishment are neither appropriate nor effective.

In addition to the presence of both motor and vocal tics, a majority of students with TS also exhibit other disorders, known as “co-morbid” or “co-existing,” such as Attention Deficit/Hyperactivity Disorder (AD/HD), Obsessive Compulsive Disorder (OCD), anxiety disorder, depression, dysgraphia (handwriting difficulty) and executive dysfunction. Some of the effects of the TS, coupled with the co-existing disorders, are dysgraphia, homework issues (sometimes a result of processing issues), issues with disorganization, time management and work completion, difficulty with transitions, anxiety, sensory processing issues, oppositional behaviors, difficulty with peers/lack of

age appropriate social skills, impulsivity, and immaturity. Often, the presentation is even more complex and confusing because the symptoms present differently at home and at school. Frequently, the symptoms of TS and its co-morbid conditions are seen as “purposeful behaviors” not related to the disability at all, when at its very core, TS is really all about a lack of control.

Substantial medical research has established that these conditions may be genetically related to TS, but too often their connection is either unknown or unrecognized by the school professionals working with students with TS. It is therefore useful to try to educate school personnel and identify as many of the TS related behaviors as possible prior to putting together a formal education plan for a child with TS.

TS is not a cognitive disorder. Children with TS often have higher than average IQs. Many will test well and achieve high grades. While relevant, good academic performance should not be the determining factor in evaluating whether a student with TS qualifies for special education or in identifying what their needs are. In fact, the special education and disability laws make clear that a student may qualify for special education or a Section 504 plan if their disability interferes with their functioning at school even if they are getting passing grades and making academic progress. Often, the most difficult parts of the school day for children with TS are the non-structured times – between classes, lunch, recess and the bus ride to and from school. It can add an extra degree of difficulty advocating for a child that is struggling the most in these non-academic areas, while functioning relatively better within the academic environment. As previously mentioned, the social and emotional struggles that occur for these children can be devastating. The schools are legally responsible for these problems whether they occur in math or lunch. It is not uncommon to be presented with a child who tics uncontrollably at times, but appears to function normally at other times. The physical and emotional toll of the disorder’s symptoms alone can have an educational impact. Even more cruel, TS symptoms tend to increase as children progress through school, seemingly getting worse at just the ages when social status and awareness peak.

Treatment for TS varies, but often includes a combination of therapy and medication. From experience, the use of medication is hit or miss. Compounding the problem is the fact that a number of current medications for AD/HD and OCD (which parents often choose to treat as the primary issue) sometimes have a potential side effect of increasing or causing tics. Similarly, medications used to treat tics are not always effective at treating the tics, and often have side effects that can compound AD/HD and OCD symptoms. So parents are sometimes left with a choice to give their children medication to treat one condition that may aggravate another, or to give a cocktail of medications to deal with all the problems that may have undesirable side effects. Students with TS may benefit from psychotherapy in order to help them understand and manage their own feelings about their TS and to deal with the emotional impact of having the disorder.

Alternative forms of treatment are sometimes used with varying degrees of success: special diets, acupuncture, and hypnosis. More recently habit reversal therapy

has been used with a degree of success for tics. Parents should use care in researching all treatment options to learn about whether there is research supporting their effectiveness and whether the side effects have been well researched. It is very important to be an informed consumer.

When children with TS present with clear speech and language issues or learning disabilities, specific services and modifications directed towards those issues are more obvious and readily available. Due to the social nature of TS, social work services are often extremely useful for children with the disorder to help them develop appropriate social skills and improve peer interactions. Having access to the school psychologist for regular meetings or during more symptomatic days is also a very good idea. Finally Occupational, Speech and sometimes Physical Therapy are often needed to address auditory and visual processing issues, sensory integration and dysgraphia.

Although parents and classroom teachers are always valuable members of the evaluation and IEP team, their roles can take on an even greater significance when planning and advocating for a child with TS. Some key steps that parents can take in working with the school team include:

- 1) Making sure that the team is adequately informed about TS in general and its potential co-morbid conditions and understands its medical basis and the many complex ways the symptoms may present themselves.
- 2) Helping the school staff to recognize the student's tics and to differentiate possible behaviors that are tics from those that likely are not. It is also helpful to work with the school team to identify situations in which tics may be more likely to express themselves and implement interventions or modifications that may alleviate some of the triggers for the tics.
- 3) Helping the school staff to accept the tics without either taking them personally, viewing them as non-compliance or deliberate, and assisting them in developing and implementing positive strategies for how to respond (or when not to respond).
- 4) Helping school staff to develop ways to inform other students about TS and the nature of tics, whether generally, or if the tics are prominent and potentially disruptive, in order to help the other students to be more sensitive and appropriate. This also helps to reduce the concern of some educators as to how to explain why behavior is "tolerated" from this student when it is not allowed for anyone else.
- 5) Regular communication between parents and school staff can also help to resolve confusion about the differing ways that the tics may occur in different settings. In addition, because tics and some of the co-morbid conditions of TS wax and wane, parent-school communication is also helpful to identify situations or times of day or times of the year that are likely to be particularly difficult for the child and can aid the child and adults to anticipate these situations and help to avoid problems.
- 6) Home-school communication is also important in relation to medication. If there is to be success with medications, monitoring effects and side effects with different doses or changes to medications is crucial.

- 7) Finally, when parents or educators identify new tics that may not be obviously recognized as tics, and communicate with each other, it can be the difference between a child with TS being disciplined for misbehaving and being provided with appropriate services or accommodations under his IEP.
- 8) It may also be helpful to have a clinician working with the student with knowledge of TS participate in school meetings and/or provide some informal staff training, as many people, including other parents and educators, are still unfamiliar with many aspects of TS. Most local chapters of the Tourette Syndrome Association offer in-services for school staffs just for this purpose.

Educational plans for children with TS should not include behavioral modification techniques or use negative consequences. In 2006, TS was added to the disabilities listed under the category Other Health Impairment in the Individuals With Disabilities Education Act regulations. Too often, children with TS were being incorrectly categorized as Emotionally Disturbed. Although children with TS appear to be misbehaving, caution must always be taken to not confuse their actions with symptoms of their disorder. Bringing attention to “negative” behaviors, like tics, will usually only serve to uncontrollably increase that behavior. Positive support with short term incentives is a much more effective approach. Children with TS are often affected by anxiety, so any modifications that can be made in the educational setting to reduce anxiety can help lessen other symptoms as well. Eliminating timed assignments and tests, reduced homework when appropriate, help managing workflow and staying organized, movement breaks when necessary and preferential seating are all common modifications.

TS is a complex and sometimes confusing disorder. The more information available to parents and educators, the more positive the school experience can be. It is important for both parents and educators to understand the nature of the disorder, how it is evaluated and treated, and effective strategies for assisting children with TS in the schools. The national Tourette Syndrome Association (www.tsa-usa.org) and TSA-Illinois (www.tsa-il.org) both offer valuable information about TS. Persons interested in more information or guidance in dealing with school issues can also contact me directly at Matt Cohen and Associates (www.mattcohenandassociates.com), 866-787-9270 or sande.shamash@gmail.com

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