

# **Guide to Tourette Disorder**

Tourette Association of America 4240 Bell Boulevard, Suite 205 Bayside, New York 11361-2820 Tel. (718) 224-2999 Fax (718) 279-9596

e-mail: tourette@ix.netcom.com

web address: http://tsa.mgh.harvard.edu

Excerpted from the author: Suzanne Bronheim, Ph.D., is an associate Professor at the Georgetown University Child Development Center

#### What is Tourette Disorder?

Tourette Disorder is a *neurobiological* disorder. Typically the symptoms of TD appear in childhood, and the most common time for the movements to begin is in the early elementary school grades. Thus teachers may be the first to observe the symptoms of TD.

There are four basic features which characterize the disorder. While these clinical features of TD are necessary for diagnosis, often there are other associated behaviors that are seen in some TD patients. These associated behaviors will be covered further along in this publication.

- 1. The child with TD exhibits involuntary multiple motor tics. These tics may be sudden twitches of the head, shoulders or even the entire body; eyeblinks or rolling of the eyes; grimacing; or repetitive tapping, drumming or touching behaviors.
- 2. The second feature of TD is what are called vocal tics involuntary uttering of noises, words or phrases. These can include sniffing, throat clearing or repeated coughing, a variety of sounds or yells, laughing involuntarily, echolalia (repeating what others or oneself has just said) and coprolalia (saying socially inappropriate words this time of vocal tic is actually *not* very common).
- 3. Another characteristic feature of TD is that the symptoms come and go.
- 4. Finally, the symptoms of TD change over time. At one age a child may exhibit eyeblinks and sniffs. The next year he may have a shoulder shrug and make clicking noises with his tongue.

Note: Children with Tic Disorder often do not display vocal + motor tics.

Note: Some tics are "ideational" or ideas which the person obsesses over or can't let go.

The tics are *involuntary*, yet, some children are able to suppress symptoms for seconds or longer depending on the individual. Thus a child with vocal tics may be absolutely quiet during church. Then, on the trip home, the tics "come out" with greater intensity and/or frequency than usual.

#### **Treatment of Tourette Disorder**

When tics are mild, a child may receive a diagnosis but no medical treatment. Acceptance of the fact that the symptoms and behaviors are not in the child's control and not purposely done to be "naughty" is sometimes enough to allow the child to function comfortably at home and at school. In some cases, however, the tics may become very disruptive and so distressing to the child that medical treatment is advisable.

Unfortunately, there is no one "magic pill" that will both eliminate the symptoms and cause no negative side effects for the child. The medications that can help also have the potential of making the child drowsy or less able to focus and learn in school. In addition, while the medications reduce symptoms, they rarely eliminate them entirely. Thus, taking medicine usually involves a trade-off.

#### Associated Disorders

For many children with TD, the tics are only problems that may affect their adjustment in the classroom. However, researchers and clinicians have observed that there is an association between TD and several other disorders which have a direct effect on behavior and learning. Many times, it will be these *other* problems that present the biggest challenge in the educational setting.

### Attention Deficit Hyperactivity Disorder (ADHD)

A high percentage of children referred for treatment of TD also have problems with attention, hyperactivity and impulse control. Many times, these are the major interfering factors in the classroom. The treatment of children with ADHD and TD is complicated, since there are questions about the effect of ADHD medications on the TD-symptoms.

#### **Obsessive-Compulsive Behaviors**

Some people with TD also have obsessive-compulsive behaviors where they have an uncontrollable urge to complete certain rituals. They may feel compelled to redo their work many times because of tine, barely perceptible imperfections. No matter what the content, the obsessions can and do "take over". In the classroom setting, obsessive-compulsive symptoms make it quite difficult to complete work in an efficient way.

#### Learning Disabilities

A disproportionately high number of children with TD also have some form of learning disability. Visual-motor integration problems that make the completion of written work difficult are quite common, but depending on the individual child, the whole spectrum of learning disabilities might be seen.

#### **Treatment of Associated Disorders**

When severe, any one of these associated disorders may require treatment by appropriate professionals. Depending on the problem, medication, psychotherapy, special education

placement or behavior modification may be tried. (Behavior modification is used to deal only with specific behavior problems. There is no evidence that behavior modification can reduce tics.) In addition, as with all children who have a chronic medical conditions, at times children with TD may need some supportive counseling to help deal with the social and physical impact of their symptoms. Proper diagnosis of each of these difficulties is needed before beginning any treatment.

### The "Typical" Child with Tourette Disorder

There is no "typical" child with Tourette Disorder. A child with TD is just that – a unique individual with some symptoms of a neurobiological disorder.

## Classroom Management of the Student with Tourette Disorder

## **Dealing with Tics**

For many students the only aspect of TD that will be evident in the classroom and at school will be the tics. The teacher's response to these tics and his/her reactions to other children's concerns about them make a critical difference. It is the teacher and other school staff who are the adults most involved in the life of a TD student. This involvement not only confers on them a serious responsibility, but also a great opportunity to have a positive and lasting impact on the TD child's adjustment and acceptance by his peers.

### **Classroom Tips**

The following are important tips for dealing effectively with the impact of TD symptoms in the classroom setting.

- 1. In some cases, the movements and noises can be annoying or even somewhat disruptive to the class\*. It is important to remember that they are occurring involuntarily. *Please do not react with anger or annoyance!* This may require patience on your part, but reprimanding the TD student is like disciplining a child with Cerebral Palsy for being clumsy. Teachers are role models for their students. Acceptance and positive regard for the child with TD is "contagious".
  - \*If some aspect of the child's tics affect the privacy or safety of others (e.g., touching others) then it is important to help find ways to work around the problem. Discipline and the TD Child (see additional resources) provides excellent suggestions to deal with this issue. Acceptance of the child is critical even when the behaviors are unacceptable.
- 2. Provide the child with opportunities for short breaks out of the classroom Time in a private place to relax and release the tics often can reduce symptoms in class. These short time out periods may also enhance the child's ability to focus on schoolwork, because the student will not be using all his or her energy to suppress the tics.
- 3. Allow the student with TD to take tests in a private room, so that the child does not waste energy on suppressing the tics during a very quite time in the classroom. Allow extra time.
- 4. Work with other students in the class and the school to help them understand the tics and reduce ridicule and teasing. School counselors, psychologists and representatives from your local Tourette Disorder Association Chapter can provide information and appropriate audio-visual materials for pupils and your colleagues.
- 5. If a child's tics are particularly disruptive, consider avoiding recitation in front of the class for a while. Be cautious about interpreting IQ and Achievements Tests as "true" indicators of capability.

- 6. Provide a structured, predictable environment with much organizational support.
- 7. Recall the child's strengths. Be certain to provide a stimulating and challenging environment.

You should remember that the student with TD is as frustrated as you are about the annoying and disruptive nature of the tics. By being the child's ally in helping to cope with this disturbing disorder and working together with the child, family and other professionals, school *can* become a positive experience.

### **Dealing with Writing Problems**

A significant percentage of children with TD also have visual-motor integration problems. Therefore, tasks that require these students to see material, process it and then write it down are very difficult and time consuming. This problem also affects copying from the board or out of a book, completing long written assignments, neatness of written work and prescribed times for completion of written work.

Even very bright TD children who have no trouble grasping concepts, may be unable to finish written work because of visual-motor impairments. Sometimes it may appear as though the student is lazy or avoiding work, but in reality the effort to get the work down on paper is overwhelming for these students.

There are a number of accommodations that can be made to help children with writing difficulties succeed in the classroom:

- 1. Modify written assignments by: having the child copy down and complete very *other* math problem; allowing the child to present a taped or oral report rather than a written one; allowing a parent or another adult to copy down work or act as "secretary" so that the pupil can dictate his ideas to facilitate concept formation. *It helps to focus on what the child has mastered and not the quantity of written work produced.*
- 2. Since the student with visual-motor problems may not be able to write quickly enough to get important information on paper, assign a "note-taking buddy" or "homework partner" who can use carbon paper to make copies of notes and assignments.
- On tests that have computer scoring sheets, allow the student to write on the test booklet. This helps avoid poor grades caused by the visual confusion that can occur when using the grid answer sheet.
- 4. Whenever possible, allow as much time as needed for taking tests. Once again, consider giving tests in another room to avoid problems with the rest of the class.
- 5. Often, students with visual-motor problems are poor spellers. Do not penalize for spelling errors, but instead, encourage proofreading and the use of a work processor with a spell checker.
- 6. Grade handwriting based on effort and not necessarily appearance.

Students with TD seem to have special problems with written math. They can be helped by encouraging the use of manipulatives in teaching math and the use of a calculator to perform rote calculations. Using grid paper with large boxes or turning regular lined paper sideways to form columns can also help the child maintain straight columns when calculating.

These accommodations can make the difference between having a motivated, achieving student, or one who feels like a failure and who will begin avoiding school work because success is never possible.

# Dealing with Language Problems – General and TD Related

Some TD children have symptoms that affect language. There are two types: language based learning problems that are common to other children, and language problems that are specifically associated with the tics of TD.

The following interventions can be helpful when dealing with language processing problems that relate to general learning disabilities:

- 1. Provide visual input as well as auditory whenever possible. The student could receive written directions as well as oral ones, or have a copy of a lecture outline to follow while listening to instructions. Pictures and graphs that illustrate the test are usually quite effective.
- 2. Give directions one or two steps at a time. When possible, ask the student to repeat the instructions to you. Then have the student complete one or two items and check with you to see if they have been done appropriately.
- 3. If you notice a student mumbling while working, try suggesting a seat where he will not disturb others. Sometimes quietly "reauditorizing" instructions or information to themselves can help students grasp and remember the assignment.

Among the language problems unique to TD; children is the repetition of their own words or those of someone else. This symptom may sound like stuttering but actually involves the utterance of words or whole phrases. Other students may exploit this problems by whispering or saying inappropriate things so that the TD student will involuntarily repeat them and get into trouble. You should be on the lookout for this provocation.

In addition, this urge to repeat can be seen in reading and/or writing activities. Students may be unable to complete work because they "get stuck" rereading or rewriting words or phrases over and over again. This is called "looping". You can monitor the student to see when this occurs. When observed, the following can be helpful:

- 1. Have the student take a short break or switch to other work.
- 2. When reading, give the child a note card with a cut out "window" that displays only one word at a time. The student slides the window along while reading so the previous word is covered and the chances of getting stuck are reduced.
- 3. When writing, have the student use pencil or pen without an eraser or allow the student to complete that work orally. Occasional reminders to move on my help.

Your ability as educators to be flexible can make all the difference in the world!

### **Dealing with Attention Problems**

In addition to learning difficulties, many TD children have varying degrees of attention deficit hyperactivity disorder (ADHD). As already noted, medical treatment for this problems is complicated. Even those who can be treated medically may still have some difficulty maintaining focus.

### A Challenge and An Opportunity

Educating a child with TD may present some interesting challenges. The more you know and understand about the disorder, the better able you will be to support that child's development. You have a tremendous opportunity to make a real difference in that child's life. Children with TS who can feel comfortable with their teachers and peers blossom in school and grow to become individuals who can develop their talents and make a positive contribution in life. Those children whose symptoms are misunderstood, or who are not supported in school, carry an enormous emotional burden. For the child, school is the arena in which one is tested. The child's sense of himself as competent, successful, likeable and valued is tremendously affected by school experiences. Your knowledge, support, patience, flexibility and caring are the best gifts you can give a child with TD.

When the classroom atmosphere encourages feelings of human kindness, tolerance and compassion, the benefits will accrue to society as a whole. The lesson isn't learned overnight, but is well worth the extended effort.

Very often dislike or rejection of another person is based on fear – usually fear of the unknown. In this case, a teacher who has taken the trouble to understand the limitations or symptomatology of a particular disability can then share with the class the knowledge and confidence acquired. This in turn can help the entire group to overcome a major stumbling block to acceptance. An older student with TD who expresses himself well, recently summed up his desires and frustrations in this way, "All I ever wanted was for my teachers to understand and accept me. Underneath my tics and noises, I'm a person just like anyone else."

Often parents, along with the physician will be measuring how much medication a child needs according to the severity of his symptoms at home. The parent might not be aware that the child's symptoms are milder at school. Parents and teachers *must maintain constant communication* so that the parent will have the benefit of a balanced assessment when trying to determine whether to decrease or increase medication.