Defining the Problem

Tourette Syndrome (TS) is a chronic neurological condition characterized by multiple motor and vocal tics that persist for more than a year. The American Psychiatric Association Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) also states that significant distress or impairment in functioning is necessary for a diagnosis of TS, but these additional criteria are controversial.

The tics—sudden, rapid, recurrent, nonrhythmic, stereotyped motor movements or vocalizations—are described as simple or complex. Simple tics, usually the first symptoms of TS, include blinking, shrugging, head jerking, sniffing, grunting, and barking. Complex tics, which involve coordinated patterns of movement or sound, may include hopping, jumping, twisting, or verbalizing words or phrases. The most dramatic complex tics are those that involve self-harm, such as punching oneself, and coprolalia, which is the uttering of obscenities. Although this is a frequently publicized symptom, it occurs in less than 10% of those with TS.

TS was once thought to be rare; it is now considered to be much more common. The transmission of TS involves multiple genetic and environmental components, but ongoing studies have not identified the specific gene responsible for vulnerability to TS. TS generally becomes evident in early childhood or adolescence, and the onset is typically between ages five and seven. The condition is 1.5 to 3 times more common in males than females. Although TS is chronic, its course waxes and wanes, and periods of remission may last for weeks and even years. The symptoms of TS may be severe, moderate, or mild. Most people experience their worst symptoms in their early teens. In many cases, the severity, frequency, and variability of the symptoms may diminish, or disappear completely, by late adolescence or early adulthood.

The most common associated symptoms that occur with TS are obsessions—persistent and intrusive thoughts, ideas, or images—and compulsions—repetitive behaviors intended to reduce anxiety. Hyperactivity, distractibility, sleep disorders, aggressiveness, and impulsivity are also linked to TS, although the reported incidence of these concurrent symptoms varies widely. Self-consciousness, social isolation, depression, and anxiety may also be present, often as a

Counseling Children and Teens with Tourette Syndrome

Treatment for children with TS should be focused on the most disabling symptoms and impaired functioning. A variety of therapeutic options have been found useful. These include:

- Support groups for children and adolescents with TS that can help them to understand the condition, improve social skills, have a supportive peer experience, and feel less socially isolated
- Psychotherapeutic counseling to develop self-esteem and self-correction
- Specific treatment techniques to address specific problem areas. These may include:
  - Social skills training that provides the child with social, emotional, and behavioral tools and strategies
  - Habit reversal that teaches the child to substitute less obvious actions for more noticeable ones
  - Relaxation training to provide relief during periods of high stress

Parents or other guardians may benefit from educational and support groups as well as parental skills training.

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Defining the Problem (continued)

consequence of concern about how others respond to witnessing tics. While learning disabilities are common in children with TS, intellectual ability is usually normal. Although tics are involuntary actions, there may be some components that respond to awareness. Some people with TS describe a compelling anticipatory urge, sometimes in a particular area of the body, that is relieved by a tic. This perception is usually not present in young children but may become more conscious as the child matures. However, when tics are inhibited, whether through conscious awareness or environmental circumstances, the period of suppression is frequently followed by a period of greater intensity and frequency of symptoms.

Fast Facts

- Tourette Syndrome was first identified in 1883 by Gilles de la Tourette, a French neurologist.
- Most TS cases are classified as mild and may require no medical treatment.
- The severity of childhood symptoms of TS is not predictive of the level of impairment as an adult. The overall outcome for children with TS is more closely related to the course of any comorbid disorders.
- Tics usually decrease in frequency and intensity during sleep.
- Although TS symptoms wax and wane, it is not degenerative and does not affect life expectancy.

What Teachers Need to Know

Working with a child or teen with Tourette Syndrome can present unique challenges, but an awareness of the specific problems that may arise in the classroom, an acceptance of the particular symptoms that might create classroom management problems, and a willingness to provide appropriate accommodation to the child with TS can make teaching a child with TS effective and rewarding.

A comprehensive plan for teaching a child with TS begins with a thorough assessment of possible academic and behavioral issues. These problems, which may be part of, or associated with TS, should be evaluated:

- Severity of vocal and motor tics. Some children may exhibit few specific symptoms during the school day, while others may have frequent episodes that can interfere with learning and classroom functioning.

- Learning disabilities. These learning issues are characteristic of children with TS:
  - Executive dysfunction. This may interfere with organizational skills, following instructions, and completing assignments;
  - Impaired fine motor skills. This may interfere with taking notes, copying homework, and written tasks;
  - Visual-motor integration problems. This can contribute to difficulties with written arithmetic, as well as other areas of academic functioning.

Standard psychological testing may not reveal the presence of these problems and neuropsychological evaluation tools are required.

- Comorbid conditions. Several conditions associated with TS can create classroom difficulties and can interfere with concentration, impulse control, and the ability to complete tasks. They include:
  - Attention deficit hyperactivity disorder (ADHD);
  - Obsessive-compulsive disorder (OCD);
  - Oppositional defiant disorder (ODD).

It's important that the teacher of a child with TS demonstrates understanding and acceptance of the condition. This can be done in several ways, including:

- Providing information so that classmates can be educated on the condition;
- Recognizing the student's talents and strengths;
- Modeling appropriate and patient responses that do not treat TS symptoms as deliberate misbehavior.

Classroom accommodations can contribute to the success of the student and the improvement of the school environment. These include:

- Providing for short breaks out of the classroom;
- Allowing the student to take tests out of the room;

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Parents of a child or teen diagnosed with Tourette Syndrome can fill several essential roles in helping their child.

**Educational advocate**
In order to guarantee that your child is receiving appropriate school services, it is important to address any difficulties that you notice related to school behavior, performance, and socialization. These can include a negative change in attitude about school, a decline in grades, reports of bullying, an increase in symptoms, or increased frustration. Parents should, as part of the educational team, insure that their child is getting effective accommodation (such as a private space for testing), effective support (such as use of a computer), and effective understanding (such as an informational program about Tourette Syndrome for students and staff).

**Service coordinator**
It is important that parents of a child with TS work to obtain all the services their child needs to make life productive and satisfying. In addition to appropriate educational services, a child with TS might benefit from:

- Psychological counseling. This can help with issues of self-esteem, social skills, and even habit reversal to help control some TS symptoms.
- Medication management. Although most children with TS do not require medication, sometimes the severity of symptoms and the comorbid conditions warrant their use. Since TS is a complex condition and the associated symptoms can be difficult to manage, it is important for parents to work with a physician familiar with treating TS.
- Occupational therapy. This can help with some specific neurological components of TS, such as visual-motor coordination.

**Emotional ally**
TS can affect a child not only by causing neurological symptoms, but by the influence those symptoms can have on the child’s sense of self and ability to function. It is critical that parents help their child develop a sense of self-esteem, negotiate social interactions, and accomplish important goals.

In order to help their child with TS, as well as the rest of the family, parents must deal with their own responses to the diagnosis. These may range from denial and guilt to anger, fear, and isolation. By combating these emotions with accurate information and effective support, parents can become their child’s most powerful ally.

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**The Dos and Don’ts of Communicating**

**DON’T**
- Tell the child to try harder.
- Label tic as "habits."
- Blame the child or yourself.
- Take the behaviors personally.
- Threaten with negative consequences.

**DO**
- Allow the child to take a break.
- Accept tics as involuntary actions.
- Focus on positive responses.
- Communicate understanding and acceptance.
- Provide constructive strategies.

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**What Parents Need to Know**

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Medication and Tourette Syndrome

Although most children with TS are not significantly disabled by their symptoms and require no medication, in more severe cases medications may be prescribed for tic remission, and for comorbid ADHD and OCD symptoms. The drugs used for tics include haloperidol (Haldol®), pimozide (Orap®), clonidine (Catapres®), clonazepam (Rivotril®) and nitrazepam (Mogadon®). Recent research has shown that for a small number of patients who prove resistant to the motor medications, injections of botulinum toxin might be helpful. Stimulants such as methylphenidate (Ritalin®) and dex- troamphetamine (Dexedrine®) that are prescribed for ADHD may temporarily increase tics and should be used cautiously. Symptoms of OCD may be controlled with fluoxetine (Prozac®), clomipramine (Anafranil®) and other similar medications.

**Medication Protocol**

- Start with a low dose and increase slowly. Experience has shown that low doses are often effective and have fewer side effects.
- Monitor symptoms and side effects in order to adjust medication dosages.
- Make changes in the medication regimen in single-step stages.
- Inform the child about use of the medication and possible side effects.

The Brain and Tourette Syndrome

Although the precise cause of Tourette Syndrome is unknown, researchers believe that dysfunctions in the central nervous system are implicated. Brain imaging techniques have revealed subtle abnormalities in the basal ganglia (which inhibit movement) and the frontal cortex (which is involved in organization and restraining inappropriate behavior) of the brain of people with TS. There is also significant evidence that TS involves ineffective regulation of neurotransmitters (responsible for communication among nerve cells), including dopamine, serotonin, and norepinephrine. Finally, scientists suspect a failure of inhibition in the frontal-subcortical motor circuits. Since the manifestations of TS are complex, it is likely that the causes of the condition are equally complex.

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<th>Books for Children and Teens</th>
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<tbody>
<tr>
<td>Managing Tourette Syndrome. Sandra Buffolano, Instant Help Publications, 2005</td>
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<tr>
<td>Don’t Think about Monkeys: Extraordinary Stories Written by People with Tourette Syndrome. Adam Seligman and John Hilkevich (Eds.), Hope Press, 1992</td>
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<th>Books for Parents</th>
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<tr>
<td>Quit it. Marcia Byalick, Yearling, 2004</td>
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<tr>
<td>Books for Professionals</td>
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<tr>
<td>Gilles de la Tourette Syndrome (2nd ed.). Arthur K. Shapiro et al, Raven Press, 1988</td>
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<tr>
<td>Tourette's Syndrome: Developmental Psychopathology and Clinical Care. J. Leckman and D. Cohen (Eds.), Wiley, 2001</td>
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