

Tourette Syndrome

Early Childhood Mental Health Fact Sheet

About the Disorder

Tourette Syndrome (TS) is a neurological disorder characterized by tics—involuntary, rapid, sudden movements and vocalizations (though they may not occur simultaneously) that occur repeatedly in the same way. For children with Tourette Syndrome (also known as Tourette's Disorder), onset typically occurs before 7 years of age, and the disorder is usually recognized two to three years after onset. In most children, the severity peaks at 9 to 11 years of age. About 5 to 10 percent of children have an intensifying course with little or no improvement. In about 85 percent of children, symptoms diminish during and after adolescence.

The symptoms include:

- Both multiple motor and one or more vocal tic(s) present at some time during the illness; however, the motor and vocal tics may not necessarily occur simultaneously;
- The occurrence of tics many times a day (usually in bouts) nearly every day or intermittently throughout a span of more than one year; and
- Periodic changes in the number, frequency, type (vocal or motor), and location of the tics; severity of the tics will wax and wane; symptoms can sometimes disappear for weeks or months at a time.

Research at the National Institute of Mental Health suggests that some cases of TS (and related Obsessive Compulsive Disorder) may be an auto-immune response triggered by antibodies produced to counter strep infection. This phenomenon is known as PANDAS. There is also a confirmed genetic basis for TS; therefore, parents seeking medical assistance for possible tic behavior in their children

should mention to their medical professionals any similar tic-like behaviors observed in other family members. Both psychiatrists and neurologists are qualified to diagnose a case of Tourette Syndrome.

What You May See

During infancy, symptoms of Tourette Syndrome are usually not evident. Around age 3, a child may begin to show motor or vocal tics. The most common first symptom in children with Tourette Syndrome is a facial tic, such as rapidly blinking eyes or twitches of the mouth. Tics of the limbs as well as involuntary sounds such as throat clearing and sniffing may also be initial signs. The tics, however, may be somewhat difficult to recognize because speech patterns and motor skills are still developing. By about age 4 when speech patterns and motor development are well established, vocal and motor tics may become more apparent. Vocal tics may include vocal outbursts, imitating or echoing the words of others, throat clearing, coughing, or snorting. Motor tics may be as simple as blinking, wrinkling the nose, or lip licking; or they may be as complex as arm or leg jerks, kicking, twirling, or fist clenching. You may also see that a child who is experiencing tics may be teased by others who don't realize that the tics are involuntary.

The complexity of some symptoms is often perplexing to family members, friends, and others who may find it hard to believe that the actions or vocal utterances are involuntary. Tics do, over time, change and vary in severity. For example, tics typically increase as a result of tension or stress, and decrease with relaxation or when focusing on an absorbing task. And although they can often be controlled or suppressed for brief periods of time, they are experienced as irresistible and, as with the urge to sneeze, eventually must be expressed.

Symptoms

- Repetitive eye blinking
- Repetitive clearing of the throat
- Repetitive coughing
- Repetitive lip licking
- Repetitive fist clenching
- Imitating or echoing the words of others
- Imitating or echoing the motions of others
- Leg jerks
- Vocal outbursts

IMPORTANT

This fact sheet is not intended to be used as a diagnostic tool. It is meant to be used only as a reference for your own understanding and to provide information about the different kinds of behaviors and mental health issues you may encounter.

While it is important to respect a child's need for confidentiality, if you work with children or families, you are legally required to report suspected child abuse or neglect. For more information, consult "Reporting Child Abuse and Neglect: A Resource Guide for Mandated Reporters," available from the Minnesota Department of Human Services.



Tourette Syndrome

(continued)

Strategies

- Interventions for a child with Tourette Syndrome should emphasize teaching the child to successfully navigate developmentally appropriate tasks. The goals should be to help the child develop friendships, experience trust, and feel competent completing activities—not stopping the tics.
- Teach relaxation and deep breathing exercises to children who are able to understand and participate in these techniques. Blowing bubbles and pretending to blow bubbles, learning to whistle, or actively trying to move their bellies in and out are all fun ways for children to learn deep breathing.
- Teach the child to tune into and identify their emotions and levels of frustration—increased frustration or anxiety can cause an increase in tic behaviors.

Common Co-Occurring Disorders with Tourette Syndrome • (adapted from www.tsa-usa.org)

Some children who have Tourette Syndrome (TS) may also have other mental health concerns.

Obsessive Compulsive Disorder (OCD)

Children may have repetitive thoughts that can become unwanted or bothersome, or they may feel compelled to do something over and over and/or in a certain way. Examples include touching an object with one hand after touching it with the other hand to “even things up” or begging for a sentence to be repeated many times until it “sounds right.”

Attention-Deficit/Hyperactivity Disorder (AD/HD)

AD/HD occurs in many people with TS. Children may show signs of hyperactivity before TS symptoms appear. Indications of AD/HD may include difficulty with concentration, failing to finish what is started, not listening, acting before thinking, shifting constantly from one activity to another, needing a great deal of supervision, and general fidgeting. AD/HD without hyperactivity includes all of the above symptoms except for the high level of activity.

Difficulties with impulse control may result, in rare instances, in overly aggressive behaviors or socially inappropriate acts. Also, defiant and angry behaviors can occur.

Sleep Disorders are fairly common among people with TS. These include difficulty getting to sleep, frequent awakenings, or walking or talking in one’s sleep.

- Do not punish the child for engaging in tics or what may appear to be strange habits such as lip licking or excessive blinking.
- Because stress can cause a child’s tics to increase, simplify the child’s environment and take steps to avoid sensory triggers such as bright lights, loud noises, or chaotic activity.

Documenting Your Concerns and Next Steps

When recording information about a child who appears to have tics, being very observant and specific is especially important. Because tics can be related to frustration and anxiety, it is also helpful to record what was happening just before the tics occurred. Avoid generalizations such as “It seems like Stephan licks his lips all day.” Instead try to associate specific events with tic behavior. For example, noting that “Stephan seemed to lick his lips when he couldn’t find the last piece to the puzzle” may give more information about what triggers tics in Stephan. Recording the frequency of the tics as well as what the caregiver said and did can help to identify areas of concern.

If a child’s behaviors are causing concern, you may want to suggest to the parents that they take their child to their primary care provider who may refer the parents to a mental health professional, an early childhood behavior specialist, or a developmental pediatrician. When discussing your concerns, focus on the child’s behaviors and avoid drawing conclusions about whether the behaviors are indicative of a mental health problem.

For more information about early childhood mental health, see MACMH’s *A Guide to Early Childhood Mental Health*, available for order at www.macmh.org.

Ready Resources

- Kami M. Talley Reading and Resource Center at the University of Minnesota offers a bibliography of resources at <http://education.umn.edu/ChildCareCenter/Kamihealingthroughbooks/>
- National Institute of Mental Health at www.nimh.nih.gov
- SAMHSA’s National Mental Health Information Center at www.mentalhealth.samhsa.gov
- Tourette Syndrome Association at www.tsa-usa.org
- ZERO TO THREE at www.zerotothree.org

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