

Tourette Syndrome

What is Tourette Syndrome?

Tourette Syndrome (TS), or Tourette's Disorder is a childhood neuropsychiatric (mental and nervous system) disorder that involves multiple tics—repetitive sudden movements (motor tics) and vocal outbursts (phonic tics) that seem largely outside of the person's control. TS is one kind of a spectrum of tic disorders that includes transient tics (tics of less than a year's duration) and chronic tics (tics typically lasting more than a year.)

TS affects each person differently. However, tics tend to occur many times each day (often in flurries), typically wax and wane in their severity, change in form over time, and may disappear for weeks or months before coming back.

What are tics like?

Tics vary greatly and can be very confusing. TS symptoms tend to emerge between five and eighteen years of age and often stop by early adulthood. They are often divided into four varieties:

- **Simple motor** - These tics are sudden, quick movements that involve a limited number of muscles and are usually repetitive. Examples: eye blinking, grimacing, shoulder shrugging and head jerking.
- **Simple phonic** - These tics are when sounds are made. Examples: throat clearing, coughing, yelping or sniffing.
- **Complex motor** – Movements that last longer and seem more purposeful. Examples: smelling things, jumping, touching or hitting others and self-injurious behaviors.
- **Complex phonic** - Tics involve repeating sounds or phrases nonsensically. Examples: emitting words or phrases out of context, counting things out loud, or more rarely, vocalizing socially unacceptable words.

What other disorders are associated with TS?

While many people only have tics, it is not unusual for people with TS to have other disorders (i.e. "TS Plus"). Some of the common problems associated with TS are obsessive compulsive disorder (OCD), attention deficit hyperactivity disorder (ADHD), learning disabilities, impulsive control difficulties, and anxiety and mood disorders.

Who gets TS?

TS was once thought to be rare, probably in part because health professionals were unfamiliar with the disorder. Many cases still go undiagnosed, but it is estimated that 100,000 Americans have severe forms of TS and that as many as one in a hundred show milder forms. It occurs in all races and ethnic groups, with males affected three to four times more often than females.

Why do people get TS?

The cause of TS is unknown, but research suggests that abnormalities in certain parts of the brain and possibly brain chemicals (neurotransmitters) involved in communication among brain cells are involved. While genetic studies show that there may be an increased risk toward tic disorders in the families of TS sufferers, recent

evidence has pointed to a possible link with autoimmune abnormalities following infectious disease (e.g. PANDAS-- Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infection).

How is TS diagnosed?

Experienced health professionals make the diagnosis by considering the person's symptom profile, individual history, and family history. There are currently no medical or psychological tests that can diagnose TS. A range of tests such as an electroencephalogram (EEG), magnetic resonance imaging (MRI), computer assisted tomography (CAT scan) or blood tests may be done to identify or rule out other conditions that may be confused with TS.

What is the prognosis?

The natural course of TS varies from individual to individual, however tics tend to occur many times each day (often in flurries), typically wax and wane in their severity, often change in form over time, and may subside for weeks or months before reappearing.

There is no cure for TS. The focus of treatment is on identifying and managing symptoms. Many cases of TS are mild and do not require treatment. TS symptoms tend to improve as individuals reach their late teens and early twenties. For some, disruptive tics can continue into adulthood and there are no reliable ways to tell how the disorder will progress in any one case. For many, disorders frequently co-occurring with TS, such as OCD, depression, ADHD and sleep disorders may cause more problems than the tics themselves.

What treatments are available?

A variety of treatments can help reduce problems from tics. These include: drug treatment and cognitive behavior therapy (CBT). Because there is a range of medicines that has been found to control TS symptoms, and because people react differently to medicines, drug treatment is best placed in the hands of doctors with plenty of experience with TS. CBT uses learning-based methods designed to increase awareness of tics, stop or lessen tics, and manage stressors that may make tics worse. However, treatment for disorders associated with TS, such as OCD and ADHD, may be a higher priority than treatment focused on management of tics.

What else helps individuals with TS?

Education, reassurance and support are extremely helpful to those with TS and their families. Better communication with families, school personnel and employers about TS can help with effective management of the disorder. The more people are educated about TS, the less social stigma exists.

Where can I find further information and help?

National Tourette Syndrome Association (www.tsa-usa.org)

Tourette Syndrome Plus (www.tourettesyndrome.net)

Tourette Syndrome Online (www.tourette-syndrome.com)

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