

# What is Tourette Syndrome?



## Tics, tic disorders, and Tourette Syndrome



Tics are involuntary, repetitive movements and vocalizations. They are the defining feature of a group of childhood-onset, neurodevelopmental conditions known collectively as Tic Disorders and individually as Tourette Syndrome, Chronic Tic Disorder (Motor or Vocal Type), and Provisional Tic Disorder. The three Tic Disorders are distinguished by the types of tics present (motor, vocal/phonetic, or both) and by the length of time that the tics have been present. Individuals with Tourette Syndrome (TS) have had at least two motor tics and at least one vocal/phonetic

tic in some combination over the course of more than a year. By contrast, individuals with Chronic Tic Disorder have either motor tics or vocal tics that have been present for more than a year, and individuals with Provisional Tic Disorder have tics that have been present for less than a year.

### Motor tics

Motor tics are tics that cause a movement. Simple motor tics include eye blinking, facial grimacing, jaw movements, head bobbing/jerking, shoulder shrugging, neck stretching, and arm jerking. Complex motor tics involve multiple muscle groups or combinations of movements and tend to be slower and more purposeful in appearance, (e.g., hopping, twirling, jumping).

### Vocal/phonetic tics

Vocal (phonetic) tics are tics that produce a sound. Simple vocal tics include sniffing, throat clearing, grunting, hooting, and shouting. Complex vocal tics are words or phrases that may or may not be recognizable but that consistently occur out of context. In 10-15% of cases, the words may be inappropriate (e.g., profanity, ethnic slurs, or other socially unacceptable words or phrases). This type of vocal tic, called coprolalia, is often portrayed or mocked in the media as a common symptom of TS; however, coprolalia is not necessary for a diagnosis of TS and, when present, is not always a permanent feature of the condition.

## Appearance and severity of TS

Tics typically emerge between the ages of 5 and 7 years, most often with a motor tic of the head and neck region. They tend to increase in frequency and severity between the ages of 8 and 12 years. Most people with TS show noticeable improvement in late adolescence, with some becoming tic-free. A minority of people with TS continue to have persistent, severe tics in adulthood.

Tics can range from mild to severe and, in some cases, can be self-injurious and debilitating. Tics regularly change in type, frequency, and severity—sometimes for reasons unknown and sometimes in response to specific internal and external factors, including stress, anxiety, excitement, fatigue, and illness.

## How many people are affected by TS?

Although TS and Tic Disorders were once thought to be rare, it has become increasingly apparent that they are common conditions. Study results vary, but the current estimates are that 1 out of every 160 children (0.6%) between the ages of 5 and 17 in the United States has TS and that 1 out of every 100 children (1%) has TS or another Tic Disorder. TS affects all races, ethnic groups, and ages but is 3 to 4 times more common in boys than in girls.

## What causes TS?

The causes of TS and other Tic Disorders remain unknown. The conditions are hereditary, so genetics clearly play a role in many, if not most or all, occurrences of the conditions. Environmental, developmental or other factors may also contribute to these disorders but, at present, no specific agent or event has been identified. Therefore, TS and Tic Disorders are likely to be caused by complex interactions between genetic and other factors that may vary in different individuals. Studies are underway to find the genes and other factors underlying the development of these disorders.



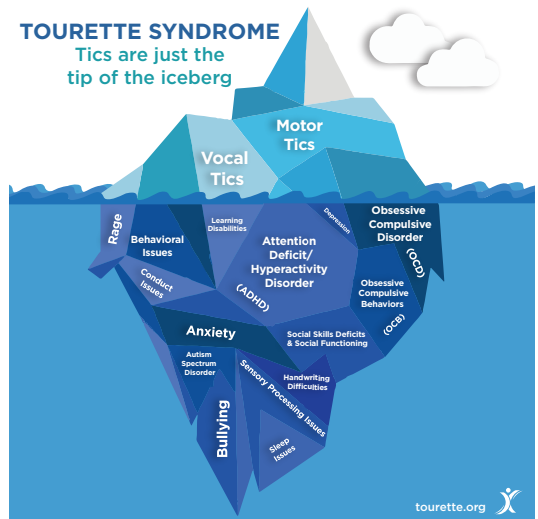
## How is TS diagnosed?

The diagnosis is made by a physician or other health care professional based on the history of symptoms. There is no biological test to confirm the diagnosis of TS, but in rare cases, tests may be necessary to rule out other conditions that mimic TS.

## What other conditions are likely to co-occur with TS?

TS commonly co-occurs with a number of other neurodevelopmental and neuropsychiatric conditions, some of which may be present before and cause more impairment than the tics themselves. The most common co-occurring conditions include the following:

- **Attention Deficit Hyperactivity Disorder (ADHD)** — Problems with concentration, hyperactivity, and impulse control.
- **Obsessive-Compulsive Disorder [or Behaviors] (OCD/OCB)** — Repetitive, unwanted or intrusive thoughts and/or repetitive behaviors. There are many types of obsessive thoughts or urges, including excessive concerns about doing something “just right,” as well as intrusive religious, sexual, or aggressive thoughts. These thoughts lead to compulsions, which are unwanted behaviors that the individual feels he/she must perform over and over or in a certain way.
- **Learning difficulties** — Difficulties related to reading, writing, mathematics, and/or processing information that are not related to general intelligence.
- **Behavior problems** — Aggression, rage, oppositional defiance or socially inappropriate acts.
- **Anxiety** — Excessive worries or fearfulness, including excessive shyness and separation anxiety.
- **Mood problems** — Periods of depression or elevated mood that result in a change in behavior or functioning, which may be significantly different from the child's usual self.
- **Social skills deficits and social functioning** — Trouble developing social skills; maintaining social relationships with peers, family members, and other individuals; and acting in an age-appropriate manner.
- **Sleeping problems** — Difficulty falling or staying asleep, bedwetting, walking or talking while asleep.



## How are TS and other tic disorders treated?

Most often, tics are mild, and treatment is not required. In all cases, it is essential to educate the individual and others in his/her life about TS and to provide appropriate support across all settings (school, work, home).

When tics become problematic or interfere with daily functioning, behavioral treatment or medication may be considered. Because each patient is unique, the individual or family should work with a clinician to determine an appropriate treatment plan. It may take some time and patience to determine the most effective approach. A clinician may recommend first treating one of the co-occurring conditions if it is more bothersome or problematic than the tics. It is usually best to begin with an effective treatment that is unlikely to cause any side effects.

## What is Comprehensive Behavioral Intervention for Tics (CBIT)?

Tested in two parallel multi-site randomized clinical trials, Comprehensive Behavioral Intervention for Tics (CBIT) is a non-medication treatment that combines elements of habit reversal training with psycho-education and function-based behavioral interventions. CBIT consists of three primary components:

- (a) training the patient to be more aware of tics;
- (b) training patients to do a competing behavior when they feel the urge to tic; and
- (c) making changes to day-to-day activities in ways that can be helpful in reducing tics



## Pharmacotherapy (medication) for tics and co-occurring conditions

Haloperidol (Haldol), pimozide (Orap), and aripiprazole (Abilify) are currently the only U.S. Food and Drug Administration (FDA) approved medications to treat tics. However, because all three medications have the potential to cause many unwanted side effects, most physicians start with “off-label” use (not FDA approved specifically for treat-



ment of tics) of guanfacine or clonidine, both of which are alpha-adrenergic agonist medications that are approved for use in the treatment of high blood pressure. These medications have been found to be moderately effective in reducing tics and to be better tolerated.

Problems with the co-occurring conditions, such as ADHD and OCD, often require medication, to improve quality of life in patients with TS. It is not unusual that treatment of these conditions can also result in a reduction of tics. ADHD symptoms of inattention, impulsivity, and hyperactivity often cause problems for school-aged children. Stimulant medications, such as methylphenidate, can be effective in children who have TS and ADHD. Other non-stimulant medications, such as guanfacine, clonidine, and atomoxetine, may also be beneficial. The selective serotonin reuptake inhibitors (SSRIs), such as fluoxetine, sertraline, and fluvoxamine, are effective in youth and adults with anxiety/OCD. Side effects are generally tolerable. If medication is recommended, make sure the clinician answers all questions about the benefits and risks.

## Deep brain stimulation (DBS)

For the most severe cases of TS, Deep Brain Stimulation (DBS) may be considered after all other appropriate treatments have been considered and failed. DBS remains an experimental surgical procedure and continues to be studied as an effective treatment.

## Do students with TS have special educational needs?



Individuals with TS are as intelligent as those in the general population, but some may have special educational needs. Tics, ADHD, OCD, learning disabilities, disruptive behavior, anxiety, and mood disorders can all interfere with learning. The use of effective treatment plans and appropriate classroom accommodations can

greatly improve the academic performance of students with TS. Those with specific learning problems often benefit from the use of specialized educational techniques that fit their learning profiles.

When school problems cannot be resolved or readily accommodated, an educational evaluation may be needed. A student with TS may benefit from having a specialized educational plan, such as a 504 Plan or Individualized Education Program (IEP). Both plans are governed by federal laws, with 504 Plans relating to Section 504 of the Rehabilitation Act and the Americans with Disabilities Act and IEPs relating to the Individuals with Disabilities Education Act (IDEA). If the child has a disability but does not require special education

services (not the same as special education classes), he/she will not qualify for an IEP but will still be eligible to receive accommodations and modifications through a 504 Plan.

While tics are involuntary, some tics may be interpreted as bad behavior or a symptom of poor parenting. Children who have tics should work with a healthcare provider and an education professional to learn strategies for managing tics in the classroom and at school.

## What is the **TOURETTE ASSOCIATION of AMERICA?**

Founded in 1972, the Tourette Association of America (formerly Tourette Syndrome Association, Inc. or TSA) is dedicated to making life better for all individuals affected by Tourette and Tic Disorders. The premier nationwide organization serving this community, the Association works to raise awareness, advance research, and provide on going support to patients and families. The Tourette Association directs a network of 32 Chapters and more than 80 support groups across the country. For more information on Tourette and Tic Disorders, call 1-888-4TOURET, visit [www.tourette.org](http://www.tourette.org), and follow Tourette Association on Facebook, Twitter, Instagram, and YouTube.



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