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# Tourette Syndrome

U.S. DEPARTMENT OF HEALTH  
AND HUMAN SERVICES  
National Institutes of Health



# Tourette Syndrome

## What is Tourette Syndrome?

**T**ourette syndrome (TS) is a neurological disorder characterized by sudden, repetitive, rapid, and unwanted movements or vocal sounds called tics. TS is one of a group of disorders of the developing nervous system called tic disorders.

There is no cure for TS, but treatments are available to help manage some symptoms.

## Onset of Tics and Duration

Tics come and go over time, varying in type, frequency, location, and severity. The first symptoms usually occur between the ages of 5 and 10 years, generally in the head and neck area and may progress to include muscles of the trunk and arms and legs. Motor tics generally occur before the development of vocal tics and simple tics often precede complex tics.

Most people with TS experience their worst tic symptoms in their early teens, but tics typically lessen and become controlled by the late teens to early 20s. For some people, TS can be a chronic condition with symptoms that last into adulthood.

Many people do not need treatment when symptoms do not interfere with daily life. Some individuals may become tic-free or no longer need medication to control their tics. In some cases, tics may worsen in adulthood. TS is not a degenerative condition (one that continues to get worse) and individuals with TS have a normal life expectancy.

## What are the signs and symptoms of Tourette syndrome?

**T**he motor (involving movement) or vocal (involving sound) tics of Tourette syndrome are classified as either simple or complex. They may range from very mild to severe, although most cases are mild.

**Simple tics:** sudden, brief, repetitive movements that involve a limited number of muscle groups. They are more common than complex tics.

**Complex tics:** distinct, coordinated patterns of movement involving several muscle groups.

### Examples of motor tics seen in Tourette syndrome

- **Simple motor tics** include eye blinking and other eye movements, facial grimacing, shoulder shrugging, and head or shoulder jerking.
- **Complex motor tics** might include facial grimacing combined with a head twist and a shoulder shrug. Other complex motor tics may appear purposeful, including sniffing or touching objects, hopping, jumping, bending, or twisting.

## Examples of vocal (phonic) tics in Tourette syndrome

- *Simple vocal tics* include repetitive throat clearing, sniffing, barking, or grunting sounds.
- *Complex vocal tics* may include repeating one's own words or phrases, repeating others' words or phrases (called echolalia), or more rarely, using vulgar, obscene, or swear words (called coprolalia).

Some of the most dramatic and disabling tics may include motor movements that result in self-harm such as punching oneself in the face or vocal tics such as echolalia or swearing. Some tics are preceded by an urge or sensation in the affected muscle group (called a premonitory urge). Some with TS will describe a need to complete a tic in a certain way or a certain number of times to relieve the urge or decrease the sensation.

### Tic triggers

Tics are often worse with excitement or anxiety and better during calm, focused activities. Certain physical experiences can trigger or worsen tics; for example, tight collars may trigger neck tics. Hearing another person sniff or clear the throat may trigger similar sounds. Tics do not go away during light sleep but are often significantly diminished; they go away completely in deep sleep.

Although the symptoms of TS are unwanted and unintentional (called involuntary), some people can suppress or otherwise manage

their tics to minimize their impact on functioning. However, people with TS often report a substantial buildup in tension when suppressing their tics to the point where they feel that the tic must be expressed (against their will). Tics in response to an environmental trigger can appear to be voluntary or purposeful but are not.

## **Disorders Associated with TS**

Many individuals with TS experience additional co-occurring neurobehavioral problems (how the brain affects emotion, behavior, and learning) that often cause more impairment than the tics themselves. Although most individuals with TS experience a significant decline in motor and vocal tics in late adolescence and early adulthood, the associated neurobehavioral conditions may continue into adulthood.

The most common co-occurring conditions include:

- **Attention Deficit Hyperactivity Disorder (ADHD)**, including problems with concentration, hyperactivity, and impulsivity.
- **Obsessive Compulsive Disorder or Behaviors (OCD/OCB)**: repetitive, unwanted thoughts, ideas, or sensations (obsessions) that make the person feel the need to perform behaviors repeatedly or in a certain way (compulsions). Repetitive behaviors can include handwashing, checking things, and cleaning, and can significantly interfere with daily life.

- **Anxiety** (fear, unease, or apprehension about a situation or event that may have an uncertain ending).
- **Learning disabilities** such as problems with reading, writing, and arithmetic that are not related to intelligence.
- **Behavioral or conduct issues**, including socially inappropriate behaviors, aggression, or anger.
- **Problems falling or staying asleep.**
- **Social skills deficits and social functioning difficulties**, such as trouble with social skills and with maintaining social relationships.
- **Sensory processing issues**, such as difficulty organizing and responding to sensory information related to touch, taste, smells, sounds, or movement.

## **Educational Settings**

Although students with TS often function well in the regular classroom, ADHD, learning disabilities, obsessive-compulsive symptoms, and frequent tics can greatly interfere with academic performance or social adjustment. After a comprehensive assessment, students should be placed in an educational setting that meets their individual needs. Students may require tutoring, smaller or special classes, private study areas, exams outside the regular classroom, other individual performance accommodations, and in some cases special schools.

## How is TS diagnosed?

To diagnose TS, a doctor looks for the following:

- Presence of both motor and vocal tics that occur several times a day, every day or intermittently for at least 1 year.
- Onset of tics before age 18.
- Tics not caused by medications, other substances, or medical conditions.

Common tics are often diagnosed by knowledgeable clinicians. However, atypical symptoms (different from classical symptoms) or atypical presentations (for example, symptoms that begin in adulthood) may require specific specialty expertise for diagnosis.

There are no blood, laboratory, or imaging tests needed for diagnosis. In rare cases, neuroimaging studies, such as magnetic resonance imaging (MRI) or computerized tomography (CT), electroencephalogram (EEG) studies, or certain blood tests may be used to rule out other conditions that might be confused with TS.

It may take some time to receive a formal diagnosis of TS. Families and physicians unfamiliar with the disorder might think mild and even moderate tic symptoms may be negligible or unimportant, a part of a developmental phase, or the result of another condition. For example, some parents may think that eye blinking is related to vision problems or that sniffing is related to seasonal allergies.



## How is TS treated?

**B**ecause tic symptoms often are mild and do not cause impairment, some people with TS require no treatment. There are effective medications and other treatments for people whose symptoms interfere with daily functioning.

### Medications

- **Medications that block dopamine** (drugs that may be used to treat psychotic and non-psychotic disorders) are the most consistently useful medications to suppress tics (for example, haloperidol and pimozide). These drugs may have or cause side effects and should be carefully managed by a physician or healthcare provider
- **Alpha-adrenergic agonists** such as clonidine and guanfacine. These medications are used primarily for hypertension (high blood pressure) but are also used in the treatment of tics. These drugs may have or cause side effects and should be carefully managed by a physician or healthcare provider.
- **Stimulant medications** such as methylphenidate and dextroamphetamine can lessen ADHD symptoms in people with TS without causing tics to become more severe. Previously, these drugs were not recommended for children with tics or TS and those with a family history of tics. Some studies show the short-term use of these drugs can help children with TS who also have ADHD.

- **Antidepressants**, specifically, serotonin reuptake inhibitors (clomipramine, fluoxetine, fluvoxamine, paroxetine, and sertraline) have been proven effective in some people to control symptoms of depression, OCD, and anxiety.

Unfortunately, there is no one medication that is helpful to all people with TS, nor does any medication completely eliminate symptoms.

**Other therapies and treatments** can include:

- **Behavioral treatments** such as awareness training and competing response training can be used to reduce tics. A recent NIH-funded, multi-center randomized control trial called Cognitive Behavioral Intervention for Tics (CBIT) showed that training to voluntarily move in response to a premonitory urge can reduce tic symptoms. Other behavioral therapies, such as biofeedback or supportive therapy, have not been shown to reduce tic symptoms. However, supportive therapy can help a person with TS better cope with the disorder and deal with the secondary social and emotional problems that sometimes occur.
- **Psychotherapy** can help individuals cope with the disorder and deal with accompanying problems or conditions, including ADHD, depression, anxiety, and OCD.

## What causes TS?

**M**ost cases of TS involve the interaction of multiple gene variations and environmental factors.

Although the cause of TS is unknown, current research points to abnormalities in certain brain regions (including the basal ganglia, frontal lobes, and cortex), the circuits that connect these regions, and the neurotransmitters (dopamine, serotonin, and norepinephrine) responsible for communication between nerve cells (called neurons).

### TS Inheritance

Evidence from twin and family studies suggests that TS is an inherited disorder. A small number of people with Tourette syndrome have mutations involving the *SLITRK1* gene, which affects how neurons grow and connect with one another, and scientists continue to look for other genes involved with TS. Abnormalities in the *NRXN1* and *CNTN6* genes, which also regulate the normal formation of these nerve connections, also may play a role in TS. Although there may be a few genes with substantial effects, it is also possible that many genes with smaller effects and environmental factors may play a role in the development of TS.

It is important for families to understand that genetic tendency may not necessarily result in TS; instead, it may express itself as a milder tic disorder or as obsessive-compulsive behaviors. It is also possible that children who inherit the gene abnormality will not develop any TS symptoms.

Genetic studies also suggest that some forms of ADHD and OCD are genetically related to TS, but there is less evidence for a genetic relationship between TS and other neurobehavioral problems that commonly co-occur with TS.

The gender of the person also plays an important role in TS gene expression. At-risk males are more likely to have tics and at-risk females are more likely to have obsessive-compulsive symptoms.

Genetic counseling of individuals with TS should include a full review of all potentially hereditary conditions in the family.

## **What research is being done?**

**W**ithin the Federal government, the National Institute of Neurological Disorders and Stroke (NINDS), a part of the National Institutes of Health (NIH), is responsible for supporting and conducting research on the brain and nervous system. NINDS and other NIH components, such as the National Institute of Mental Health, the *Eunice Kennedy Shriver* National Institute of Child Health and Human Development, the National Institute on Drug Abuse, and

the National Institute on Deafness and Other Communication Disorders, support research of relevance to TS, either at NIH laboratories or through grants to major research institutions across the country.

Another component of the Department of Health and Human Services, the Centers for Disease Control and Prevention (CDC), funds professional education programs as well as TS research.

Knowledge about TS comes from studies across numerous medical and scientific disciplines, including genetics, neuroimaging, neuropathology, clinical trials (medication and non-medication), epidemiology, neurophysiology, neuroimmunology, and descriptive/diagnostic clinical science.

**Genetic studies.** Currently, NIH-funded investigators are conducting a variety of large-scale genetic studies involving TS. Understanding the genetics of TS genes may strengthen clinical diagnosis, improve genetic counseling, lead toward a better understanding of its causes, and provide clues for more effective therapies.

**Neurostimulation.** NINDS-funded research is testing the effectiveness and safety of deep-brain stimulation (DBS) for treating tics and co-occurring conditions, such as obsessive-compulsive behaviors, in individuals with TS who do not respond well to medications and behavioral therapy. DBS uses a surgically implanted, battery-operated medical device called an implantable pulse generator

(IPG)—similar to a heart pacemaker and approximately the size of a stopwatch—to deliver electrical stimulation to specific areas in the brain that control movement, which blocks the abnormal nerve signals that cause symptoms.

**Neuroimaging studies.** Advances in imaging technology and an increase in trained investigators have led to an increasing use of novel and powerful techniques to identify brain regions, circuitry, and neurochemical factors important in TS and related conditions, such as ADHD and OCD.

**Neuropathology (the study of nervous system diseases).** There has been an increase in the number and quality of donated brains from TS patients available for research purposes. This increase, coupled with advances in neuropathological techniques, has led to initial findings with implications for neuroimaging studies and animal models of TS.

**Clinical trials.** Several clinical trials in TS recently have been completed or currently are underway. These include studies of stimulant treatment of ADHD in TS and behavioral treatments for reducing tic severity in children and adults. Smaller trials of novel approaches to treatment such as dopamine agonists and glutamatergic medications also show promise. Neurostimulation treatments such as DBS and noninvasive transcranial magnetic stimulation in children and adults are also ongoing.

**Epidemiology and clinical science.** Careful epidemiological studies (those that track the pattern or incidence of a disease) now estimate the prevalence of TS to be substantially higher than previously thought, with a wider range of clinical severity. Furthermore, clinical studies are providing new findings regarding TS and co-existing conditions. These include subtyping studies of TS and OCD, an examination of the link between ADHD and learning problems in children with TS, and a new appreciation of sensory tics. One of the most important and controversial areas of TS science involves the relationship between TS and autoimmune brain injury associated with group A beta-hemolytic streptococcal infections or other infectious processes. There are many epidemiological and clinical investigations currently underway in this area.

### **How can I help with research?**

**C**onsider joining a clinical study. Both healthy individuals and those with a disease or condition can participate in medical research studies (sometimes called clinical trials or protocols) to help researchers better understand a disease and perhaps develop new treatments. For information about clinical studies on disorders including Tourette syndrome and how to participate in one, please contact the **NIH's Patient Recruitment and Public Liaison office** at 800-411-1222 or visit the [Clinicaltrials.gov](http://www.clinicaltrials.gov) website at <http://www.clinicaltrials.gov>.

## Where can I get more information?

**F**or more information on neurological disorders or research programs funded by the National Institute of Neurological Disorders and Stroke, contact the Institute's **Brain Resources and Information Network (BRAIN)** at:

### **BRAIN**

P.O. Box 5801  
Bethesda, MD 20824  
800-352-9424  
<https://www.ninds.nih.gov>

**Other NIH research efforts.** More information about research on Tourette syndrome supported by NINDS and other NIH Institutes and Centers can be found using NIH RePORTER ([www.projectreporter.nih.gov](http://www.projectreporter.nih.gov)), a searchable database of current and past research projects supported by NIH and other federal agencies. RePORTER also includes links to publications and resources from these projects. Enter "Tourette syndrome" to start your search.

Information also is available from the following organizations:

### **Child Neurology Foundation**

201 Chicago Avenue, Suite 200  
Minneapolis, MN 55415  
612-928-6325  
<http://www.childneurologyfoundation.org>

### **Tourette Association of America**

42-40 Bell Boulevard, Suite 205  
Bayside, NY 11361-2820  
718-224-2999; 888-486-8738  
<https://tourette.org>



## **U.S. Centers for Disease Control and Prevention (CDC)**

Information and statistics on Tourette Syndrome

800-232-4636

<https://www.cdc.gov/ncbddd/tourette/index.html>

## **MedlinePlus**

National Library of Medicine

National Institutes of Health

<https://medlineplus.gov>







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