



New Jersey Center for
Tourette Syndrome
and Associated Disorders, Inc.



Misunderstood,
misdiagnosed,
and much more
common than
you think

Questions and Answers to help you better understand Tourette Syndrome



More than 28,000 kids in New Jersey exhibit symptoms of Tourette Syndrome

1. Q. What exactly is Tourette Syndrome?

A. Tourette Syndrome (TS) is a neurological disorder characterized by tics - involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The symptoms include:

1. Both multiple motor and one or more vocal tics present at some time during the illness although not necessarily simultaneously;
2. 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
3. Periodic changes in the number, frequency, type and location of the tics, and waxing and waning of their severity. Symptoms can sometimes disappear for weeks or months at a time.
4. Onset before the age of 18.

The term "involuntary" used to describe TS tics is sometimes confusing since it is known that most people with TS do have some control over their symptoms. What is not recognized is that the control, which can be exercised anywhere from seconds to hours at a time, may merely postpone more severe outbursts of symptoms. Tics are experienced as irresistible and (as with the urge to sneeze) eventually must be expressed. People with TS often seek a secluded spot to release their symptoms after delaying them in school or at work. Typically, tics increase as a result of tension or stress, and decrease with relaxation or when focused on an absorbing task.

TS is not degenerative; intelligence and life span are no different from that of the general population.

2. Q. How would a typical case of TS be described?

A. The term typical cannot be applied to TS. The expression of symptoms covers a spectrum from very mild to quite severe. However, the majority of cases can be categorized as mild.

3. Q. Is obscene language (coprolalia) a typical symptom of TS?

A. Definitely not. The fact is that cursing, uttering obscenities and ethnic slurs are manifested by fewer than 15% of people with TS. Too often, however, the media seize upon this symptom for its sensational effect.

4. Q. What causes the symptoms?

A. The cause has not been established, although current research presents considerable evidence that the disorder stems from the abnormal metabolism of at least one brain chemical (neurotransmitter) called dopamine.

5. Q. How is TS diagnosed?

A. A diagnosis is made by observing symptoms and by evaluating the history of their onset. No blood analysis or other type of neurological testing exists to diagnose TS. However, some physicians may wish to order an EEG, MRI, CAT scan, or certain blood tests to rule out other ailments that might be confused with TS.

6. Q. What are the first symptoms?

A. The most common first symptom is a facial tic, such as rapidly blinking eyes or twitches of the mouth. However, involuntary sounds, such as throat clearing and sniffing, or tics of the limbs may be the initial signs. For some, the disorder can begin abruptly with multiple symptoms of movements and sounds.

7. Q. How are tics classified?

A. Tics can be simple or complex and are generally grouped into categories as follows:

SIMPLE MOTOR TICS:

Eye blinking, body jerking, facial grimacing, head jerking, shoulder shrugging

SIMPLE VOCAL (OR PHONIC) TICS:

Sniffing, throat clearing, humming, tongue clicking, whistling, yelping

COMPLEX MOTOR TICS (appear purposeful): Jumping, smelling, touching other people or things, twirling and rarely, copropraxia (demonstrating socially inappropriate gestures)

COMPLEX VOCAL (OR PHONIC) TICS (appear purposeful): Saying words or phrases out of context (oh boy!), stuttering and rarely, coprolalia (vocalizing socially unacceptable words)

The range of tics or tic-like symptoms that can be seen in TS is very broad. The complexity of some symptoms is often perplexing to family members, friends, teachers and employers who may find it hard to believe that the actions or vocal utterances are involuntary.

8. Q. How is TS treated?

A. The majority of people with TS are not significantly disabled by their tics or behavioral symptoms, and therefore do not require medication. In instances where TS symptoms interfere with daily functioning, medications may be prescribed. There is no one specific drug for the treatment of Tourette Syndrome, and each individual responds differently to drug therapies; but a number of medications have shown great results in controlling specific symptoms of Tourette Syndrome. (For more information, consult with a physician.)

Other types of therapy may also be helpful in the treatment of individuals with TS. Psychotherapy can assist a person with TS and help his/her family cope, and some behavior therapies can teach the substitution of one tic for another that is more acceptable. The use of relaxation techniques and/or biofeedback may serve to alleviate stress reactions that cause tics to increase.

9. Q. Do all people with TS have associated behaviors in addition to tics?

A. No, but many individuals with TS do have associated conditions which may include:

ATTENTION DEFICIT DISORDER WITH OR WITHOUT HYPERACTIVITY (ADD OR ADHD): Symptoms include all or most of the following: poor impulse control, hyperactivity, fidgetiness, inattention, poor concentration or disorganization. These symptoms may be noticed before TS symptoms appear.

OBSESSIVE COMPULSIVE DISORDER (OCD): Obsessions are involuntary, persistent thoughts which are unwanted or bothersome, such as the fear of something bad happening to someone, or nonsense thoughts. Compulsions are ritualistic behaviors that might involve excessive checking, counting, feeling the need to even things up, or doing something until it is "just right". Some individuals may exhibit compulsions only.

LEARNING DISABILITIES (LD): are significant difficulties with reading, math, written expression, oral language and/or listening comprehension.

EXECUTIVE DYSFUNCTION: may include difficulty planning, organizing, being flexible and/or prioritizing.

SLEEP DISORDERS: may include difficulty falling asleep and staying asleep, walking or talking in one's sleep, or difficulty waking up.

MOOD DISORDERS: include depression, bipolar disorder, anxiety disorders.

10. Q. Do students with TS have special educational needs?

A. While school children with TS as a group have the same IQ range as the population at large, some have special educational needs. Data shows that many may have some kind of learning problem. The impact of learning disabilities, combined with Attention Deficit Disorder and the difficulty coping with tics, often calls for special education assistance. The use of recording devices or computers for reading and writing problems, untimed exams (in a private room if vocal tics are a problem) and permission to leave the classroom when tics become overwhelming are often helpful. Some children need extra help, such as access to tutoring in a resource room.

When difficulties in school cannot be resolved, an educational evaluation may be needed. A resulting identification as "other health impaired" under federal law will entitle the student to an Individual Education Plan (IEP) which addresses specific educational problems in school. Such an approach can significantly reduce the difficulties that prevent a student from performing at his/her potential.

11. Q. Is TS inherited?

A. Genetic studies indicate that TS is inherited as a dominant gene that causes varying symptoms in different family members. A person with TS has about a 50% chance with each separate pregnancy of passing the gene to one of his/her children. However, that genetic predisposition may express itself as TS, as a milder tic disorder or as obsessive compulsive symptoms with no tics at all. It is known that a higher than normal incidence of milder tic disorders and obsessive compulsive behaviors occur in the families of those with a TS diagnosis.

The sex of the offspring also influences the expression of the gene. The chance that the gene-carrying child of a person with TS will have symptoms is at least three to four times higher for a son than for a daughter. Yet only about 10% of the children who inherit the gene will have symptoms severe enough to ever require medical attention. In some cases, TS may not be inherited and cases such as these are identified as sporadic TS. The cause in these instances is unknown.

12. Q. Is there a cure for TS?

A. Not yet.

13. Q. Is there ever a remission?

A. Many people experience marked improvement in their late teens or early twenties. Most people with TS get better, not worse, as they mature and those diagnosed with TS can anticipate a normal life span.

14. Q. How many people in the US have TS?

A. Since many people with TS have yet to be diagnosed, there are no absolute figures. The official estimate by the National Institute of Health is that 200,000 Americans have full-blown TS. Some genetic studies suggest that the figure may be as high as 1 in 200 if those with chronic multiple tics and/or transient childhood tics are included in the count.

15. Q. What is the history of TS?

A. Dr. George Gilles de la Tourette, the French neurologist for whom the disorder is named, first described a French noblewoman with the disorder in 1885.

16. Q. What is the current focus of research?

A. Since 1984, the Tourette Syndrome Association has directly funded important research investigations in a number of scientific areas relevant to TS. Recently, studies have intensified to understand how the disorder is transmitted from one generation to the next and researchers are working toward locating the gene marker for TS.

Additional insights are being obtained from studies of large families (kindreds) with numerous members who have TS. At the same time, investigators continue to study specific groups of brain chemicals to better understand the syndrome and to identify new and improved medications.

In 2007, the NJCTS Sharing Repository was established. This unique resource makes human cell and DNA samples available to qualified researchers from around the world who are studying the role that genetics play in causing TS, and searching for better ways to treat Tourette Syndrome and its associated disorders.

17. Q. What types of services exist for families with TS?

A. To help individuals and families, the New Jersey Center for Tourette Syndrome and Associated Disorders, Inc. was formed with the purpose of providing...

- *Coordinated services for families dealing with TS*
- *Education and awareness for the public and professional communities*
- *Training for a new generation of professionals*
- *Support for research to find better treatments and a cure for TS*

The New Jersey Center for Tourette Syndrome and Associated Disorders, Inc. is a resource for individuals, families and professionals dealing with Tourette Syndrome



**New Jersey Center for
Tourette Syndrome**
and Associated Disorders, Inc.

NJCTS presents a model program—the only one of its kind in the nation—to provide an innovative and comprehensive approach to treatment and support for the thousands of New Jersey families living with Tourette Syndrome.

NJCTS was created in 2004 as a collaboration among TSANJ, Rutgers University and health professionals throughout New Jersey.

Services provided through NJCTS include:

- *Medical diagnosis and treatment.*
- *Medication management.*
- *Psychological services.*
- *Coordinated patient care among partner and community organizations throughout the state.*
- *On-site in-service training for education professionals.*
- *Education and training to develop a new generation of professionals knowledgeable about TS and associated disorders.*
- *Hospital grand rounds, seminars and other educational programs for physicians, educators and allied professionals.*
- *NJCTS Sharing Repository—the world's first sharing resource of human cells and DNA for Tourette Syndrome research. Samples are made available to qualified researchers around the world to study the genetics of TS and work toward a cure.*
- *Family services including advocacy, education and support programs.*

If you or a family member is living with TS and would like information about our programs, please call 908 575 7350 or visit www.njcts.org for details.



**New Jersey Center for
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A collaboration among TSANJ,
Rutgers University and health
professionals throughout New Jersey

For more about **NJCTS** programs and referrals call:

908 575 7350

or visit

www.njcts.org

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