

The New Jersey Center for Tourette Syndrome
and Associated Disorders (NJCTS)



**New Jersey Center
for Tourette Syndrome**

and Associated Disorders, Inc

Collaborative Partnerships for the
Tourette Syndrome Community



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**A comprehensive resource for individuals,
families and professionals dealing with
Tourette Syndrome, NJCTS provides:**

- Referrals for medical diagnosis and treatment
- Referrals for psychological services
- Coordinated family support among partner and community organizations throughout the state
- Education and training at medical schools and universities to develop a new generation of New Jersey professionals knowledgeable about TS and associated disorders
- Outreach to practicing physicians, educators and allied professionals
- Research into causes and effective treatments for TS and associated disorders
- The nation's only university-based, stand-alone TS psychological clinic, located at Rutgers University
- The world's first TS DNA and cell repository, making genetic material available to qualified researchers worldwide to understand factors that may lead to treatments and cures

If you would like information about our programs, please call 908 575 7350 or visit www.njcts.org for details.



**Misunderstood,
misdiagnosed
and much more
common than
you think**

**Understanding
Tourette
Syndrome**



Tourette Syndrome (TS) is a neurological disorder that causes those who have it to make uncontrollable sounds and movements called tics. TS affects as many as 1 in 100 kids and adults.

Some tics are physical and some are vocal, and people with TS may demonstrate one, the other or both.

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.

The term "involuntary" 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.

Symptoms that lead to a diagnosis include:

- at least two motor tics and one vocal tic
- tics that persist for more than one year
- tics that begin before the individual is 18 years old

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.

Tics can be simple or complex, and are generally grouped into categories:

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)

There may be 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.

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

What causes the symptoms?

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.

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 hands may be the initial signs. For some, the disorder can begin abruptly with multiple symptoms of movements and sounds.

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

Not always, but many individuals with TS do have associated conditions which may include:

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 non-sense 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): Significant difficulties with reading, math, written expression, oral language and/or listening comprehension.

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

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

MOOD DISORDERS: Depression, bipolar disorder, anxiety disorders.

How is TS treated?

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 symptoms of TS or symptoms of related disorders 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 positive results in controlling symptoms of Tourette Syndrome, ADHD, OCD, anxiety and other disorders. (For more information on medications consult with a physician.)

Other types of therapy may also be helpful. 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.

Do students with TS have special educational needs?

School children with TS as a group have the same IQ range as the population at large, but many have special educational needs. Tics, ADHD, anxiety and mood disorders can all interfere with focus and learning; and the difficulty coping with the symptoms, 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.

Is TS inherited?

Genetic studies indicate that TS is inherited as a dominant gene and that a person with TS has about a 50% chance of passing the gene to one or more of his/her children.

This genetic predisposition may express itself as TS, as a milder tic disorder or as obsessive compulsive symptoms with no tics at all.

Can an infection cause TS?

It's been suggested that in some very rare cases, tics may suddenly start after a beta-hemolytic streptococcal infection, but this has not been proven and more studies are being conducted to determine if there is, in fact, a connection.

Can TS be cured... does it ever go away?

There is no known cure for TS, but a lot of progress has been made in understanding the best treatments for reducing the severity and impact of TS and its related symptoms.

Many people experience marked improvement in their late teens or early 20s.

Most people with TS get better as they mature and those diagnosed with TS can anticipate a normal life span.

How common is TS?

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 well over 200,000 Americans have full-blown TS. Some genetic studies suggest that the figure may be as high as 1 in 100.

What is the current state of TS research?

With findings of genetic links, current studies are focused on better understanding how the disorder is transmitted from one generation to the next.

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 and treatments.

In 2007, with the help of NJCTS, the world's first TS Cell and DNA Sharing Repository was established at the Life Sciences Institute at Rutgers University. This unique resource makes human cell and DNA samples available to qualified researchers from around the world to study the role that genetics play in causing TS, and search for better ways to treat Tourette Syndrome and its associated disorders.

If you, or a family member of yours has been diagnosed with TS, please participate in the NJCTS Cell & DNA Sharing Repository research program. It is important to obtain as much data as possible in order to find better treatments and a cure.



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