

The range of tic symptoms can be very broad. The complexity is often perplexing to family members, friends, teachers and employers who may find it hard to believe that these symptoms are involuntary.

How is TS diagnosed?

Diagnosis is made by observing symptoms and/or evaluating a description of the movements and their onset. Blood tests or other types of neurological testing cannot confirm a diagnosis of TS. However, some medical professionals may order such tests to rule out other conditions that might be confused with TS.

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

No, but many do have other problems which may include:

Obsessions — repetitive unwanted and intrusive thoughts. There are many types of obsessive thoughts including concerns about dirt and germs and intrusive religious, sexual or aggressive thoughts.

Compulsions and rituals — unwanted behaviors a person feels must be performed over and over and/or in a certain way. Examples include excessive washing or grooming rituals, checking that a stove or iron is turned off or a door locked, ordering and arranging objects until it appears or feels “just right” or “evened-up.”

Attention Deficit and Hyperactivity Disorder — there are three hallmark symptoms of ADHD: inattention, hyperactivity and impulsivity; and three diagnostic categories primarily inattentive type, primarily hyperactive/impulsive type and the combined type. Children may show signs of ADHD before tics first appear. ADHD often, but not always, persists into adulthood.

Learning disabilities — reading, writing, perceptual and arithmetic difficulties. These problems have nothing to do with intelligence levels.

Behavior control problems — aggression, anger, defiance or socially inappropriate acts.

Sleeping problems — difficulty falling or remaining asleep, bedwetting, walking or talking while asleep.

Anxiety disorders — excessive worries including separation anxiety, excessive shyness or generalized fearfulness or worry.

Mood disorders — periods of depressed or irritable mood (depression) or elevated mood (mania) that is a distinct change in behavior and uncharacteristic for the person.

Developmental disorder — children who have problems or deficits in their capacity for interpersonal relationships, communication with others and who have restricted, stereotyped interests or developmental unusual interest.

How is TS treated?

Most of the time, TS symptoms are mild and do not require treatment. When tics are disabling, treatment may be considered, but finding the right medication can be difficult because no one medication works for everyone, and dosages can vary with each patient. Medications that are used to treat tics include alpha adrenergic agonists (e.g. Catapres and Tenex®), and neuroleptics (e.g. Haldol®, Prolixin®, Orap®, Risperdal®, Geodon®, Abilify®). Usually medication is started at a low dosage and increased gradually over time. During this period, symptom improvement and medication side effects (such as sedation, depression, restlessness, weight gain, fatigue) should be carefully monitored by the treating physician. Sometimes (if the conditions are more disabling) the treatment will target the comorbid conditions and not necessarily the tics.

Other types of therapy may be helpful, but have not been well studied. These include supportive counseling, behavioral therapy, and relaxation training techniques such as biofeedback. By reducing stress, these treatments may reduce tic severity.

When to treat?

Tic suppressing medications should be considered when symptoms are severe and disabling. For example, patients with symptoms that are physically uncomfortable, are disruptive at school or work, or lead to stigmatization will often seek medication treatment to reduce the severity of their tics. It is not uncommon for patients to try tic suppressing medications and then discontinue them because the side effects outweigh the potential benefit of treatment.

How are co-morbid conditions treated?

There are several medications available to treat the co-morbid conditions of TS. A discussion of these medication options is beyond the scope of this brochure, but is available in the *Consumer's Guide to Medications*.

However, when ADHD symptoms affect learning, medications for ADHD may be warranted. For most people, stimulant medications used for ADHD, such as methylphenidates (e.g. Ritalin®, Concerta® and Metadate®) and amphetamines (e.g. Adderall® and Dexedrine®) do not worsen tics. However, given that tics wax and wane in severity, symptoms may worsen after starting treatment with stimulant medications. In some children with TS and ADHD, problems with ADHD appear before the onset of tics. Consequently these children may start taking the stimulant medication at around the same time that the tics first appear, and sometimes people assume that the stimulant medication caused the tic.

In addition to reducing tics, alpha adrenergic agonists such as clonidine (Catapres®) and guanfacine (Tenex®) may be useful in treating ADHD. However, the beneficial effect may not be apparent for several weeks after beginning the medication. A newer medication atomoxetine (Strattera®) may also be useful in children with both TS and ADHD.

For treating obsessive compulsive symptoms that interfere significantly with daily functioning, antidepressant medications such as fluoxetine (Prozac®), clomipramine (Anafranil®), sertraline (Zoloft®), fluvoxamine (Luvox®), paroxetine (Paxil®), citalopram (Celexa®), escitalopram (Lexapro®) may be prescribed. These medications can also be useful for anxiety disorders and depression. Other antidepressants such as bupropion (Wellbutrin®/Zyban®), nefazodone (Serzone®), mirtazapine (Remeron®), the tricyclic antidepressants can be useful for depression and/or anxiety.

Do students with TS have special educational needs?

While children with TS are as intelligent as those in the general population, many have special educational needs. Tics, ADHD, learning disabilities, disruptive behavior, anxiety and mood disorders all can interfere with learning. Treatment to reduce these underlying problems can be helpful in improving the educational outcomes of children with TS. For those with specific

learning problems, the use of tape recorders or computers, untimed exams (sometimes in a private room) and permission to leave the classroom when tic symptoms become overwhelming often are helpful to these students.

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. This approach can significantly reduce the learning difficulties that are preventing the young person from performing at his/her potential. Those who cannot be adequately educated in a public school with special services geared to his/her individual needs may be served best by enrollment in a special school.

Is TS inherited?

Recent genetic studies indicate that the underlying genetic mechanisms for TS are more complex than originally thought. We've learned that several genes may be implicated and that environmental factors also affect the outcome. The gene or genes responsible for TS may be expressed as either TS, as a milder tic disorder, as obsessive compulsive symptoms or may not be expressed at all. Males are four times more likely to express tic symptoms than females. Females are more likely to express obsessive compulsive symptoms. As many of the conditions co-occurring with TS are also inherited, affected individuals are encouraged to be knowledgeable about all the different medical and psychiatric disorders that appear to run in their family.

Can an infection trigger TS?

There is some evidence that in a very small subgroup of people tics may emerge suddenly following a Group A, Beta-hemolytic streptococcal infection (i.e. strep). This subject is controversial, and more studies are needed to clarify this suspected association.

Is there a cure?

Not yet, but treatments to reduce tic severity and the symptoms of co-occurring conditions can be very useful. Enormous strides have been made in research casting light on the basic causes of the disorder.

Is there ever a remission?

Most people experience marked improvement in their late teens or early twenties and some even experience a remission. Only a small percentage of people have very severe and persistent tics into adulthood.

How many people in the U.S. have TS?

Until the 1970s, TS was thought to be very rare. With increased awareness more people with milder symptoms are coming to clinical attention. It is the nature of TS that tics are more common in children than adults. Mild to moderate cases of TS are more common than severe cases. Depending on the study, estimates can range from 1/100 for milder cases to 1/1000 for more severe cases.

What is the current focus of research?

Since 1984, the TSA has directly funded research in a number of relevant scientific areas including neuroimaging, neuroimmunology, neurochemistry, neurophysiology, neuropathology, neuroanatomy, clinical trials, epidemiology, genetics, psychology and animal model development.

In addition to its individual investigator awards, the TSA supports several international groups of scientists who work together and share new information about specific aspects of TS. These different groups are focusing on genetics, behavioral therapies, neuroimaging and other clinical studies.

What is the Tourette Syndrome Association (TSA)?

Founded in 1972, TSA is the only national voluntary non-profit membership organization whose mission is to identify the cause, find the cure and control the effects of Tourette Syndrome through education, research and service.

Members include individuals with the disorder, their relatives and other interested, concerned people. Our

programs of research, professional and public education, and family services are made possible through the generosity of our donors.

What does TSA do?

- Maintains an Internet website (<http://tsa-usa.org>) to keep you informed and answer your questions
- Helps families in crisis through its Information and Referral Service
- Promotes public awareness and understanding of TS
- Develops and maintains state-by state lists of doctors and allied professionals (e.g. psychologists, social workers, counselors) for referral purposes
- Maintains an active teacher education program and provides guidance to parents on effective lobbying strategies for IEP programs
- Organizes workshops and symposia for scientists, clinicians and others working in the field of TS. Increases the knowledge and sensitivity of health care professionals to TS through exhibits at conferences and dissemination of literature at national meetings
- Represents the interests of members to the government on critical policy issues including orphan drugs, health insurance and employment
- Publishes a quarterly newsletter and produces brochures and video tapes that discuss in detail many of the topics touched upon in this pamphlet. For a full list and description, please consult our website at <http://tsa-usa.org>

What type of support is there for families?

There are TSA regional chapters and support groups in most areas of the USA. These local groups provide resources and support that allow families to exchange ideas and feelings about their common problems. Please contact us to obtain information about the chapter in your area.

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This brochure is intended to provide basic information about TS. It is not intended to nor does it constitute medical advice. Readers are warned against changing medical schedules or life activities based on this information without first consulting a physician.



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