

Why is TS misinterpreted?

Tics can sometimes be suppressed

Tics may need to be repeated until they 'feel just right'

Tics may subside while extremely focused or when the person is doing such activities as:

Participating in a sport

Working on a computer

Playing a musical instrument
(*This is not true for all people with TS*)

Misrepresentation of TS in the Media — inaccurate portrayal that all individuals with TS swear and make inappropriate remarks

How can I help?

Be patient and accepting—tasks take longer

Decrease stress and anxiety— avoid pressured situations

Ignore tics— Not the person

Don't say "Stop It"—this can increase tics

Make accommodations for tics

Eliminate triggers

Keep a routine schedule—reduces anxiety

Communicate transition prior to switching and **assist** during the process

Communicate clearly—rules and requests

Pick your battles wisely—not everything matters!

Understand reactions are disability based, not a plan to be rude or offensive

Educate peers—to promote acceptance

Be aware & prevent teasing and bullying

Respect the individual—talk with them; let them know you are aware of TS and it's ok to "tic"

The Pennsylvania Tourette Syndrome Alliance, Inc. (PA-TSA)

is a non-profit organization whose mission is to identify, support the needs of and advocate for individuals with Tourette Syndrome in Pennsylvania.

To promote awareness of Tourette Syndrome through informational outreach and educational presentations.



PA-TSA is a 501(c)(3) non-profit organization.

PA Tourette Syndrome Alliance, Inc.

P.O. Box 148
McSherrystown, PA 17344

(717) 337-1134

1-800-990-3300

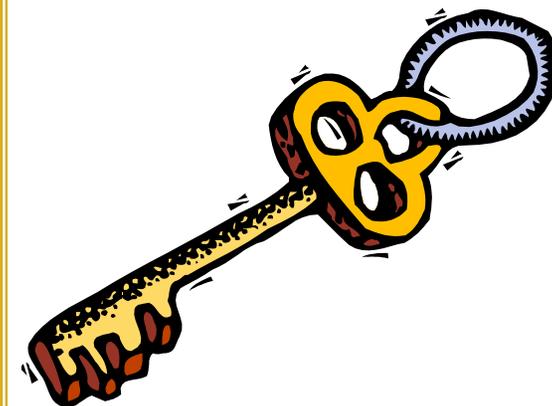
Fax: (717) 698-1420

www.patsainc.org

PA Tourette Syndrome Alliance, Inc. is not associated with the Tourette Syndrome Association, Inc. located in Bayside, New York.



TS Primer



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Tourette Syndrome (TS)

is an inherited, neurological disorder characterized by tics.

Vocal & Motor Tics

Involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way.

Vocal Tics

Sniffing
Coughing
Yelling
Grunting
Repeating Phrases
Echoing words

Motor Tics

Blinking
Moving head
Rolling Eyes
Jumping
Hopping
Tapping

These are examples of possible tics and not a complete list!

Tics can be ANY Action, Movement or Sound!

Tics wax and wane and change in their location, frequency, and intensity.

**Swearing or making inappropriate remarks can be a tic, however this affects only 5-15% of those with TS.

This is called Coprolalia and is **not** needed for diagnosis.

Mental Tics

In addition to the Motor and Vocal tics, most individuals with TS also have mental tics.

Mental tics are involuntary intrusive words, thoughts, ideas or images that can be pleasant or scary. Mental tics may cause an individual to be distracted, appear to be daydreaming or cause quick mood changes. The person may perseverate on a certain topic or appear to have a "one track mind".

When an individual is bothered by mental tics of morbid, violent or sexual images, they may feel the need to "get them out" by expressing them verbally, writing about them or depicting the images in artwork or doodles.

Diagnosis

Individuals are often diagnosed by a Neurologist or Psychiatrist. Currently there are no medical tests that can prove the diagnosis, but tests are often performed to rule out other conditions.

Diagnostic Criteria: Both multiple motor and one or more vocal tics present at some time during the illness, but not necessarily concurrently. Tics may wax & wane in frequency but have persisted for more than 1 year from first tic onset. Onset is before the age of 18. Tics are not due to a direct physiological effect of a substance or any other illness such as Huntington's disease.

Research shows that up to 1 in every 100 children between the ages of 6 and 17 could have TS. Diagnosis most often occurs between the ages of 7 and 10.

Course

Tourette syndrome is a life long disorder which affects each person differently. Many report a decrease in symptoms in adulthood, however a small percentage report no change in symptoms. The tics of Tourette Syndrome tend to wax and wane, and often increase due to stress, anxiety, excitement, and puberty.

Medical Treatment

Pharmaceutical Therapy—there are only 2 medications that are FDA approved to treat TS, however there are many other medications that are prescribed to treat the many symptoms of TS. These medications vary in their effectiveness and have a number of side effects which should be considered.

It is the opinion of many doctors, family members and individuals with TS that medications should be used only to treat tics that impede daily living, the ability to learn or work, or are physically or emotionally harming to the individual.

Associated Conditions

Attention Deficit Disorder (ADD)
Attention Deficit Hyperactivity Disorder (ADHD)
Obsessive-Compulsive Disorder (OCD)
Anxiety Disorders/ Phobias
Mood Disorders/Depression
Autism Spectrum
Learning Disabilities
Dysgraphia-handwriting disorder
Slow Processing Speed
Eye Tracking Problems
Executive Dysfunction
Sensory Processing Difficulties
Oppositional Defiant Disorder (ODD)
Rage Attacks
Panic Attacks
Sleep Disorder
Social Skills Deficit
Migraines

ADD/ADHD
75%

OCD
60%

Other Possible Characteristics

Quick temper / Overreaction
Problems with organization
Handwriting difficulties
Impaired attention
Over-activity
Mood fluctuations
Rigid thinking
Argumentative
Need to have last word
Speaks or Acts before thinking
Difficulty with transition
Perception problems—social interactions
Sensitive to noises/light/touch/feel of clothing or may crave certain sensations