

TOURETTE SYNDROME

What is it?

Tourette Syndrome (TS) is a neurological disorder characterized by repetitive, involuntary, and purposeless contractions that cause movements and vocalizations called tics. Early symptoms are often first seen in childhood around the ages of 3-9 years. Males are 3-4 times more likely to be affected than females. Involuntary movements usually first appear in the face as a facial tic like eye blink, nose twitch or grimace.

According to DSM-5 criteria, the following criteria is needed for a person to be diagnosed with TS:

- At least 2 motor tics and at least 1 vocal tic have been present, not necessarily at the same time
- Tics may wax and wane in frequency but have occurred for more than 1 year
- Tics started to appear before the age of 18
- Tics are not caused by the use of a substance or other medical condition

People with TS often have co-occurring mental, behavioral, or developmental conditions. Such conditions may be present prior to the onset of tics. These conditions may include: ADHD, OCD, anxiety, aggression, sleep disorders, sensory proceeding issues, learning disability, and social skills deficits.

What are the symptoms?

Tics can vary in severity, frequency, type and location. They often worsen with excitement, stress or anxiety. They do not go away with sleep but are greatly diminished. Symptoms often worsen and reach their peak throughout the teen years but can improve into adulthood.

Motor tics are tics that cause movement and can be classified as simple or complex. They often precede vocal tics. Simple motor tics are brief, sudden and usually involve a limited number of muscle groups. Simple motor tics include eye blinking, facial grimacing, jaw movements, head bobbing/jerking, shoulder shrugging, neck stretching, and arm jerking. Complex motor tics involve multiple muscle groups or a combination of movements and tend to be slower and more purposeful in appearance. Common complex motor tics can include facial grimacing combined with head positioning, hopping, twirling, and jumping.

Vocal or phonic tics are tics that produce a sound. Simple vocal tics include sniffing, throat clearing, grunting, whistling, and shouting. Complex vocal tics are words or phrases that may or may not be recognizable but that consistently occur out of context. In some cases, words may be inappropriate (i.e., swear words, ethnic slurs, or other socially unacceptable words or phrases).

TS commonly co-occurs with a number of other neurodevelopmental and neuropsychiatric conditions. Some may actually present before a TS diagnosis and cause more impairment than the tics themselves. Associated neurobehavioral problems may persist into early adulthood despite a significant decline in motor and vocal tics.



Kennedy Krieger Institute

The **Specialized Health Needs Interagency Collaboration (SHNIC)** program is a collaborative partnership between the Kennedy Krieger Institute and the Maryland State Department of Education.

Suggested school accommodations

Supporting students with this condition in the school require educators and parents/guardian to work as a team. Some accommodations to consider for a 504/IEP could include:

- Promote communication with caregivers
- Flash pass/ emotional support
- Seating that allows student to leave classroom if necessary
- Frequent breaks
- Consider transition time, crowded hallways, etc.
- Private area testing
- Assistive technology
- Copies of notes
- Extended time for assignments
- Strategies for stress reduction
- Identify skill deficits that lead to stress
- Ignore symptoms that can be ignored
- Build schedule around student's most productive time of day
- Consider impact of motor tics on handwriting
- Consider impact of vocal tics and oral presentations
- If vocal tics, allow a "safe haven" area for student to go to release tics
- Staff education and training as appropriate
- Emergency Evacuation Plan (EEP) as it relates to motor tics

Specific health issues for Individualized Healthcare Plan

- Diagnosis including age of onset, other co-occurring diagnosis
- Current medication list for home and school; note any potential side effects like weight gain, cardiac, tremors, cardiac abnormalities
- Baseline neurological and cardiac assessment
- Child specific characteristics of tics
- Plan to identify and communicate potential new tics
- Open communication plan with caregiver that includes identifying stressful life events
- Plan to monitor for bullying, depression, etc.
- Plan to monitor and keep student safe if leaving classroom for release period or "safe haven"
- Communicate with school staff, parents/guardian, and provider any changes or concerns about the disease
- Emergency Care Plan(s) (ECP) related to medical needs in the school setting and staff education/training as appropriate for each

Resources & Manuals

Kennedy Krieger Institute: Tourette Syndrome Center of Excellence
<https://www.kennedykrieger.org/tourette-syndrome-center-of-excellence>

Tourette Association of America
<http://tourette.org/index.html>

National Institute of Neurological Disorders and Stroke: Tourette Syndrome factsheet
http://www.ninds.nih.gov/disorders/tourette/detail_tourette.htm

Tourette Syndrome of America: Resources for educators
http://tourette.org/Education/education_main.htm#foreducators