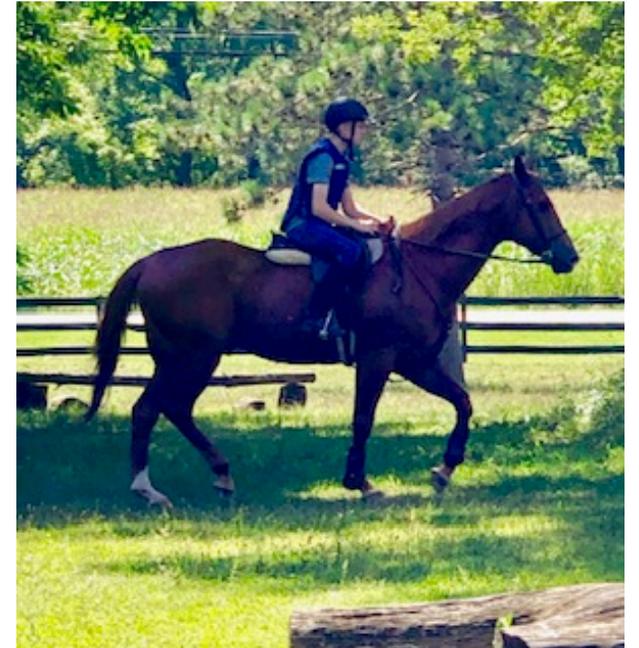


Understanding Tourette Syndrome and Co-Occurring Conditions

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Welcome and Introductions

- Teacher for 25 Years
- My son, MY Teacher



Learning Objectives

- Understand the prevalence of Tourette Syndrome and other Tic Disorders
- Basics of tics
- Co-occurring conditions
- Recommendations for remote and 2020-2021 in-person learning.



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Overview of Tourette Syndrome

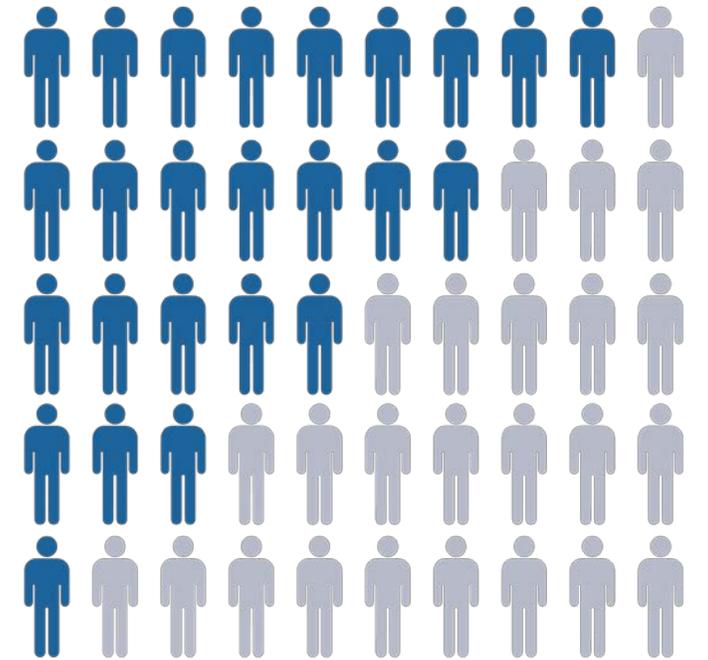
Prevalence of Tourette Syndrome



1 out of every **160** children (0.6%)
between the ages of 5 and 17
in the United States
has Tourette Syndrome



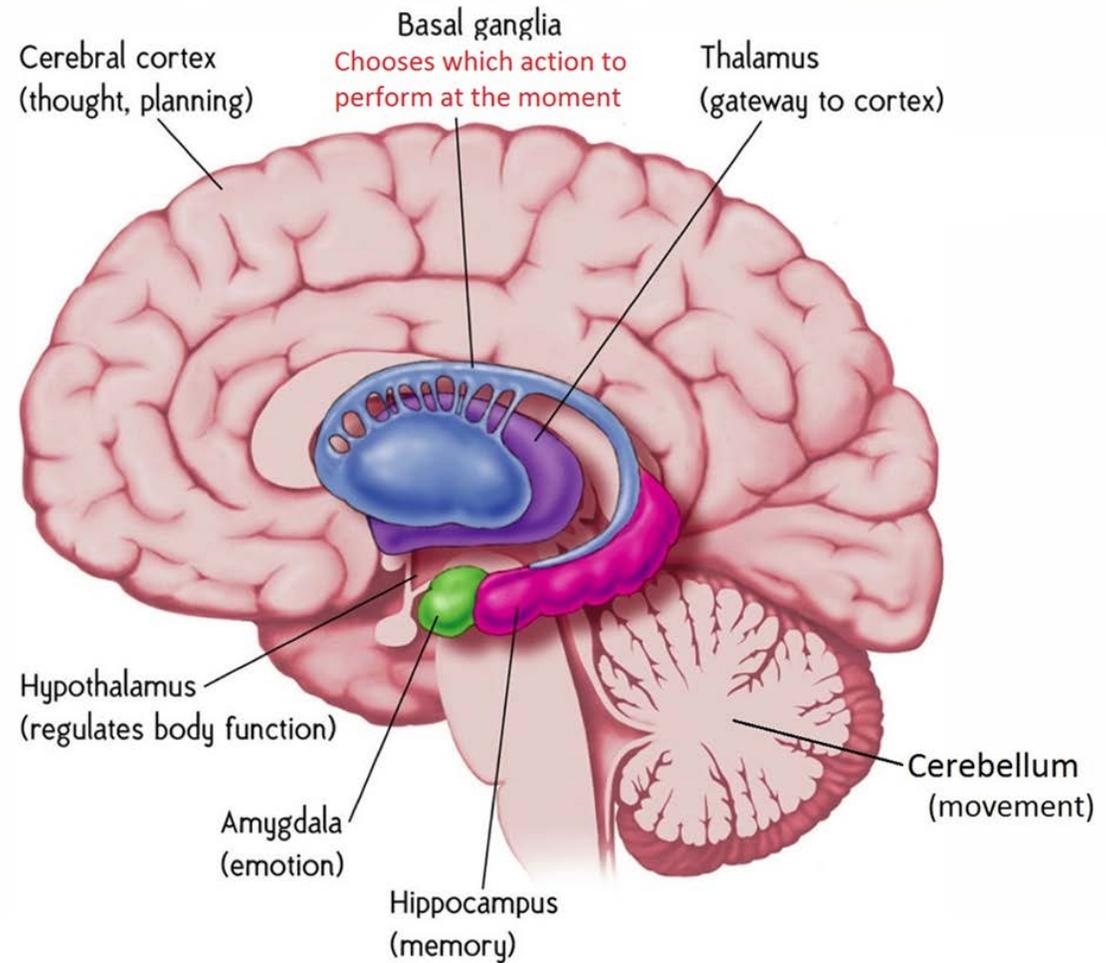
1 out of
every **100**
children (1%)
has Tourette
Syndrome
or another
Tic Disorder



An estimated 50% go undiagnosed

Neurodevelopmental Disorder

Disability of disinhibitory



Neurodevelopmental



- Tics are typically noticed when a child is between the ages of 5 and 7.
- Tics typically increase in frequency and severity when a child is between 8 and 12 years old.
- Most people with TS show noticeable improvement in late adolescence. Some become tic-free.
- Approximately one-quarter of people with TS continue to have persistent, severe tics into adulthood.

Tics

- Involuntary, repetitive movements and vocalizations
- Feels like a physiological urge that is hard to ignore or suppress. Tics provide only temporary relief of the urge.
- Tics can range from mild to severe and can be self-injurious and debilitating.
- Tics regularly change in type, frequency, and severity.

It sort of feels like when you have to sneeze... you know you have to, and it's all you can think about until you do.

Types of Tics: Motor tics

Simple motor tics

- Usually involve just one group of muscles
- Examples:
 - Eye blinking
 - Facial grimacing
 - Jaw movements
 - Head bobbing/jerking
 - Shoulder shrugging
 - Neck stretching
 - Arm jerking



Complex motor tics

- Usually involve multiple muscle groups or combinations of movements
- Examples:
 - Hopping
 - Twirling
 - Jumping
 - Sticking out the tongue
 - Kissing
 - Pinching
 - Tearing paper or books

Types of Tics: Vocal tics

Simple vocal tics

- Examples:
 - Sniffing
 - Throat clearing
 - Grunting
 - Hooting
 - Shouting



Complex vocal tics

- Words or phrases that may or may not be recognizable; can occur in and out of context
- Some specific vocal tics:
 - Coprolalia: outburst of obscene words or socially inappropriate and derogatory remarks
 - Echolalia: repeating words or vocalizations of others
 - Palilalia: repeating one's own syllables, words, or phrases

Managing Tics at School

- Planned ignoring – compare to drip of a faucet.
- Breaks can look different for different students
- Use accommodations as needed – ex: for testing
- Tics become less disruptive when everyone knows that they are going to occur and why they occur
- Anxiety will be reduced for the student with TS and can result in increased academic performance.

Complex Symptoms: Difficult to Recognize, Support, and Understand

- Symptoms can change or wax and wane.
- Stress increases symptoms.
- Symptoms can be suggestible.
- The ability to suppress symptoms is inconsistent and can vary from one person to the next.
- A student may struggle to manage the symptoms of TS, co-occurring conditions, or both.

The only thing consistent about Tourette Syndrome is the inconsistencies!

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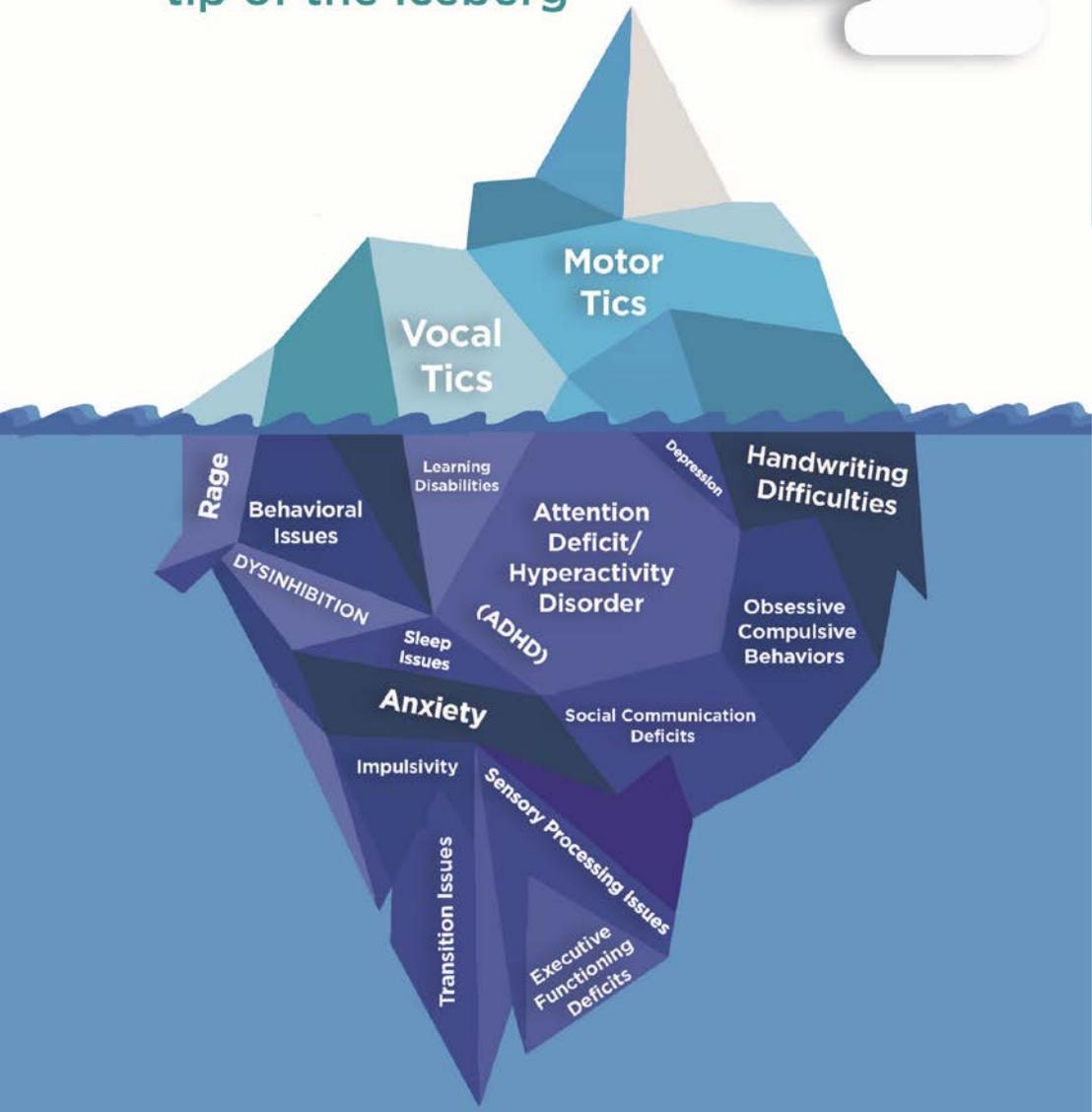
Co-Occurring Conditions

TOURETTE SYNDROME

Tics are just the tip of the iceberg



Common Co-occurring Conditions



Tourettic Obsessive Compulsive Disorder/Obsessive Compulsive Behaviors

“Classic” Obsessive Compulsive Disorder (OCD): An individual’s symptoms are linked with ritual compulsive behaviors in an attempt to manage the anxiety and fear the individual experiences related to the obsessions.

Tourettic OCD: The symptoms overlap more closely with the individual’s experience of tics. The individual has a need to do or say things in a certain way or at a given time, or until things feel just right. The behavior is driven by an urge rather than by fear.

*Both types are common in children with TS.

Social Communication Disorder

When an individual has deficits in the social use of language but does not have the restricted interests or repetitive behavior seen in autism spectrum disorders.

Social Communication Disorder is a matter of **pragmatic use of language**, not mechanics.

Students with social communication deficits may experience or exhibit:

- Difficulty understanding and following rules of storytelling
- Difficulty with metaphors, inferences, humor
- Desire for friends
- Poor eye contact
- Rigidity in their perceptions
- The ability to describe what they should do in a one-to-one interaction with someone, but the failure to interact in that way "in the moment"

Sensory Processing Disorder

Students who have TS who also have sensory issues may experience or exhibit:

- Feeling overwhelmed by too much sensory input in loud and/or chaotic environments (e.g., cafeteria, recess, PE, music, art)
- The need for excessive sensory input
- Chewing on clothes or body
- Excessive touching, hitting, hurting self, jumping, or kicking

An Occupational Therapist can recommend strategies for a “Sensory Plan” individualized for the student.

Executive Function Challenges (including ADD/ADHD)

Executive Function: A set of mental processes that help connect past experience with present action and enable individuals to perform activities such as planning, organizing, strategizing, and paying attention to and remembering details, all while managing time and space.

Executive function challenges that benefit from support:

- With transitions
- Beginning and completing tasks/assignments
- Remembering what to do
- Decreasing rigidity and recognizing that others have different opinions
- Developing lifelong strategies to demonstrate true abilities

Anxiety

- Anxiety has a cumulative effect during the day.
- Students with Tourette Syndrome need to manage tics, their attempts to suppress tics, their anxiety, and co-occurring challenges.
 - When students are not sufficiently supported to manage their anxiety, there is often an undesirable reaction and outcome.
 - Work with the student to recognize when they are overloaded and when they can use strategies to help reduce their anxiety.
- Clinical anxiety and subclinical stress/anxiety can both exacerbate tics.

Oppositional Defiant Disorder (ODD)

- A child's response to stress
 - Child or teen demonstrates difficulty with emotional regulation
 - Child or teen demonstrates a flight or fight response in certain situations; the behaviors are not purposeful
- Can appear in children with traumatic backgrounds as well as those from stable, loving families.
- View ODD a symptom and provide support for the cause of the behavior.
- Trusted relationships are most important in supporting the child or teen.

“Over the years I have come to believe that Oppositional Defiant Disorder is not a label that should be used to describe young children.”

- Mona Delahooke, PhD

Written Language Deficits

Written language deficits or dysgraphia characteristics may include:

- Slow and laborious writing
- Sloppy handwriting (e.g., uneven spacing, irregular margins, and inconsistent lettering)
- Incorrect capitalization or punctuation
- Inability to copy correctly from book to paper or board to paper
- Inability to organize thoughts on paper
- Perfectionism

To evaluate, have the student write at length on a non-favorite topic during a time of day that is typically difficult for them.

Supporting Students with Tourette Syndrome

It's important to focus on what we can do *for* the student *prior* to the behavior instead of what we do *to* them *after* the behavior has occurred.

-Dr. Ross Greene

Reasons a Child May Engage in Challenging Behavior

- Boredom
- Fatigue
- Frustration
- Feeling overwhelmed
- Feelings of failure
- Sensory overload
- Executive function deficit
- Poor planning skills
- Specific or generalized skills deficit
- Response to a symptom (e.g., OCD/OCB, sensory issues, ADHD, anxiety)
- Trying to fit in; desire to have friends
- Disinhibition

Support During Remote Learning

- Make sure your child has a designated and well-organized workspace
- Make sure the seat is comfortable and the computer is adjusted to eye level
- Post a color-coded schedule in his or her workspace
- Match colored folders to colored schedule
- Learn to use their virtual platform: Google Classroom, Schoology, etc
- Use a dry erase board or a notebook to write assignments, check them off when complete
- Keep folders and extra paper in a basket
- Keep supplies in a separate basket

Support During Remote Learning

- Have a basket of sensory supplies at your child's workstation
- Some suggestions are playdough, squishy balls, fidget spinners, Rubik's cube, small bean bags
- Have your child do sitting exercises while listening like pressing hands together, pulling fingers, pushing up on your seat
- Alternative seating options may include standing – pile books for computer to be at eye level – sitting on a bean bag, or spreading out on the floor
- Build in movement breaks – moving to a dance video, short yoga video, stretches, jumping jacks, any light exercises

Support During Remote Learning

Practice mindfulness with your child or teen:

- Draw a square breathing in and out for four counts
- Place one hand on your heart, one on your belly, breath in and out for 3 counts for one minute
- Close your eyes and spend one-minute thinking about things or people you appreciate
- Close your eyes and spend one-minute thinking about people that make you feel good
- Close your eyes and spend one to three minutes and go from focusing on what you hear to just paying attention to your breath.

Support Offered by the Tourette Association of America

- [Tools for Educators](#): Comprehensive education resources for parents, children, and teachers
- [Tools for Parents](#): Advice, guidance, and valuable information for parents of children with Tourette Syndrome or other Tic Disorders
- [Find a Local Chapter or Support Group](#): Searchable by state
- [Youth Ambassador Program](#): A teen education, empowerment, and advocacy program
- [Youth Ambassador-Rising Leaders Program](#): A young adult professional and personal development program
- [In-Person Trainings for Various Audiences](#): For the general community, educators, medical providers, and CBIT
- [Find a Provider](#): Searchable by state and other filters
- [Tools for Medical Practitioners](#): Information on diagnosis, treatment, and research
- [Tools for Law Enforcement](#): Training materials related to Tourette Syndrome
- [TAA Centers of Excellence](#): Designated medical institutions that offer expert clinical care, research, training, education, and community outreach

Thank you!



Survey



<https://www.surveymonkey.com/r/taafblive>