

MANAGING TOURETTE & TIC DISORDERS

A Guide to Treatment for Care Providers





Diagnosing and Treating Tourette Syndrome & Tic Disorders



PROVIDING AN ACCURATE DIAGNOSIS

Tics are involuntary, repetitive movements and vocalizations. They are the defining feature of a spectrum of childhood-onset, neurodevelopmental conditions known collectively as Tic Disorders and individually as *Tourette Syndrome (TS)*, *Persistent (Chronic) Motor or Vocal Tic Disorder*, and *Provisional Tic Disorder*.

These three Tic Disorders are distinguished by the types of tics present (motor, vocal/phonic, or both) and by the length of time that they are present. Below are the criteria that are used for identification and differential diagnostic purposes.¹ A diagnosis is made by a physician or other health care professional based on the history of symptoms. There is no biological test to confirm the diagnosis of TS, but in some cases, tests may be necessary to rule out other conditions.

Tourette Syndrome (TS), also referred to as Tourette's Disorder

- 1) Both multiple **motor** and 1 or more **vocal** tics have been present at some time during the disorder, although not necessarily concurrently.
- 2) Tics may wax and wane in frequency but have persisted for more than 1 year since first tic onset.
- 3) Onset is before age **18** years.
- 4) The disturbance is not attributable to the physiological effects of a substance or another medical condition

Persistent (Chronic) Motor or Vocal Tic Disorders

Single or multiple motor OR vocal tics have been present, but not both.

Provisional Tic Disorders

Single or multiple motor and/or vocal tics. Tics have been present for less than 1 year, and criteria have not been met for TS or persistent (chronic) motor or vocal tic disorder.

¹ Criteria are modified from the American Psychiatric Association: Diagnostic and Statistical Manual of Mental Disorders, 5th edition. Arlington, VA., American Psychiatric Association, 2013.



CLASSIFICATION OF TICS

CLASSIFICATION	SIMPLE	COMPLEX
Motor Tics Some Examples:	SUDDEN, RAPID, NON-RHYTHMIC MOVEMENTS: Eye blinking, head shaking, face grimacing, shoulder shrugging, abdominal tensing, or arm jerking	MOVEMENTS ARE OFTEN SLOWER AND MAY SEEM PURPOSEFUL IN APPEARANCE: Touching, tapping, hopping, squatting, skipping, jumping, or <i>copropraxia</i> (obscene gestures)
Vocal (Phonic) Tics Some Examples:	SUDDEN, OFTEN MEANINGLESS, SOUNDS OR NOISES: Sniffing, coughing, spitting grunting, throat clearing, snorting, animal noises, squeaking, shouting	WORDS OR PHRASES THAT OFTEN OCCUR OUT OF CONTEXT: Syllables, words or phrases (“shut up”, “stop that”), <i>*coprolalia</i> (uttering of obscenities), <i>palilalia</i> (repeating own words), <i>echolalia</i> (repeating others’ words)

OTHER IMPORTANT CHARACTERISTICS OF TICS

- They can change in type, intensity, and location.
- They often increase with stress, excitement, anxiety, and fatigue.
- Some may be suppressed, but only temporarily.
- They may be reduced during calm, focused activities.
- They can be preceded by a **premonitory urge**, described as a *sensory or mental sensation preceding tics*.

***Only 1 in 10 patients have coprolalia. The presence of coprolalia is not necessary for a Tourette diagnosis.**

COURSE & SEVERITY OF TS

Tics typically emerge between the ages of 5 and 7 years, most commonly with a motor tic in the head or neck region. They tend to increase in frequency and severity between the ages of 8 and 12 years. Tics can range from mild to severe. Many individuals with TS show noticeable improvement in late adolescence, with some becoming tic-free. A minority of individuals with TS continue to have persistent, severe tics into adulthood.



PREVALENCE OF TS AND TIC DISORDERS

- **Tics** are common and occur in as many as **1 in 5** school-aged children.
- **TS and Persistent Tic Disorders** occur in an estimated **20 cases per 1,000 (2% or 1:50)**, suggesting that more than 1,400,000 children have a Tic Disorder in the United States.
- **TS** occurs in **6 cases per 1,000 (0.6% or 1:160)** children, meaning approximately 300,000 children have the condition in the United States. There is a lower prevalence for a diagnosis of TS since tics often go unrecognized. TS affects all races, ethnic groups and ages, but is **3-4 times more common in boys** than in girls.
- There are no reliable prevalence estimates of TS and other Tic Disorders in adults. However, they are expected to be much lower than in children because tics often decline into late adolescence.

1 in 50

At least 1 in 50 children have Tourette Syndrome or tics.

CAUSES OF TS

The causes of TS and other Tic Disorders remain unknown. These conditions tend to occur in families, and numerous studies have confirmed that there is a genetic link. Environmental, developmental, or other factors may also contribute to these disorders but, at present, no specific agent or event has been identified. Researchers are continuing to search for the genes and other underlying factors contributing to the development of Tic Disorders.

TAKE A FULL MEDICAL HISTORY

When conducting an assessment of your patient, observe any signs of tics and common co-occurring conditions, such as anxiety, Obsessive-Compulsive Disorder (OCD), or Attention Deficit/Hyperactivity Disorder (ADHD). Ask about a family history of tics and other neuropsychiatric conditions. Too often, patients have already been assessed by an allergist for symptoms such as sniffing or throat clearing, or they might have seen an ophthalmologist for eye-blinking. The behavioral symptoms are often mislabeled as emotional disturbances or attention-seeking behaviors. Many health care providers still erroneously assume coprolalia is necessary for a diagnosis of TS. These are all causes for delay in providing an accurate diagnosis. A comprehensive understanding of TS can lead to early identification and provide appropriate care for your patient.



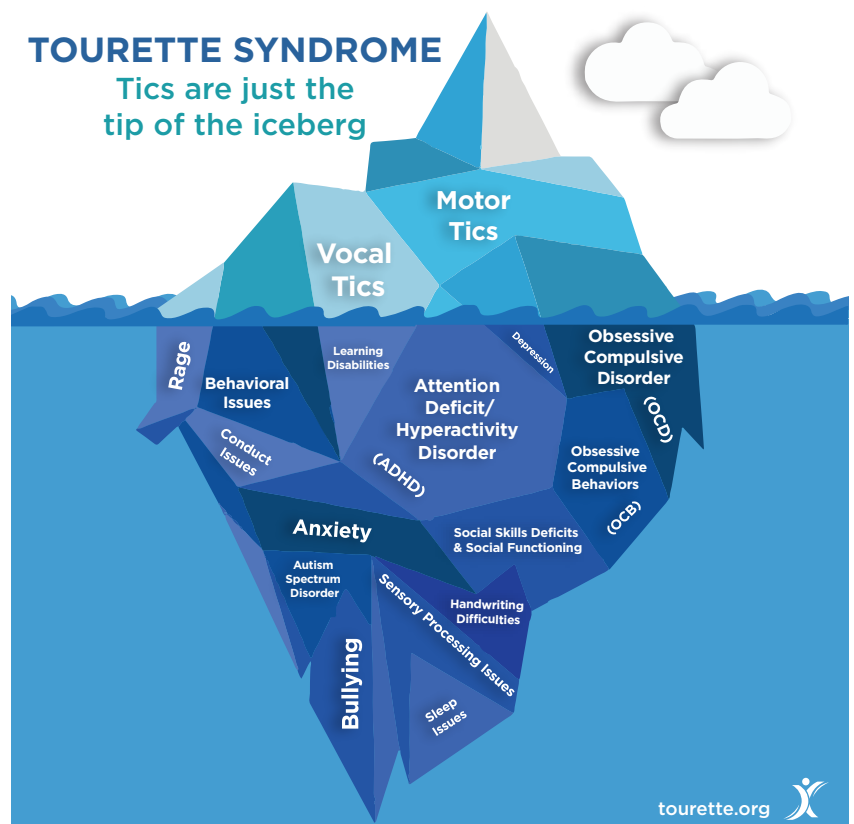
LOCATING A PROVIDER KNOWLEDGEABLE ABOUT TOURETTE AND TIC DISORDERS

The Tourette Association of American (TAA) maintains a state-based referral listing of medical and allied professionals experienced in TS management. Additionally, the Tourette Association Centers of Excellence (CofE) program works with premier medical institutions around the country that offer expert and coordinated care. Please refer to the “Support” section of this kit for more information about the Centers of Excellence, or contact the Tourette Association at tourette.org or by calling **888-4TOURET**.

COMMON CO-OCCURRING CONDITIONS

TS often co-occurs with a number of other neurodevelopmental and neuropsychiatric conditions, some of which may be present prior to the onset of tics. While tics are the primary symptom, these other co-occurring conditions may cause more impairment and can be more bothersome than the tics themselves. Among children diagnosed with TS, an estimated 86% have also been diagnosed with at least one additional mental, behavioral, or developmental condition. The most common co-occurring conditions include the following:

- **Attention Deficit/Hyperactivity Disorder (ADHD):** Problems with concentration, hyperactivity, and impulse control.
- **Obsessive-Compulsive Disorder or Behaviors (OCD/OCB):** Repetitive, unwanted intrusive thoughts and/or repetitive behaviors. These thoughts lead to compulsions, which are unwanted behaviors that the individual feels he/she must perform over and over or in a certain way.
- **Behavioral or Conduct Issues:** Aggression, rage, oppositional defiance or socially inappropriate behaviors.
- **Anxiety:** Excessive worries or fearfulness, including excessive shyness and separation anxiety.
- **Learning Disability:** Reading, writing, mathematics, and/or information processing difficulties that are not related to intelligence.
- **Social Skills Deficits and Social Functioning:** Trouble developing social skills; maintaining social relationships with peers, family members, and other individuals; and acting in an age-appropriate manner.
- **Sensory Processing Issues:** Strong sensory preference and sensitivities related to sense of touch, sound, taste, smells, and movement that interfere throughout the day.
- **Sleep Issues:** Trouble falling or staying asleep.



DIFFERENTIAL DIAGNOSES - HOW DO I DIFFERENTIATE BETWEEN A TIC AND OTHER MOVEMENTS?

Differential Diagnosis of Common Hyperkinetic Movement Disorders

Movement Disorder	Character of the Movement	Premonitory Urge	Suppressibility	Distractibility	Occurrence During Sleep	Common Etiology, Associated Features
Tics	Jerk-like movements, involuntary sounds or phrases, multifocal, simple or complex and sequential	++++	+++	+++	+++	Tourette Syndrome, Tic Disorder, Attention Deficit Disorder, Obsessive Compulsive Disorder, impulse control problem
Chorea	Jerk-like, brief, random, generalized, unable to maintain tongue protrusion	0	+	+	0	Huntington Disease May affect mood, cognition, speech, gait and balance
Myoclonus	Jerk-like, brief, segmental or generalized	0	+	0	++	Post-anoxic
Dystonia	Sustained, repetitive and patterned contractions producing abnormal postures or movements, focal, segmental, generalized, hemidystonia	0	++	+	++	DYT1 and other genetic, sporadic or secondary dystonias Dystonic tremor
Tremor	Rhythmic, oscillatory movement, during rest or action	0	+	+	+	Parkinson's Disease, Essential tremor

0 = no or none; ++++ = frequently marked

The table summarizes key differences between Tics and other hyperkinetic movements, and may serve as a guide in the differential diagnoses of movement disorders that are encountered in clinical practice. Premonitory urges are sensory or mental sensations preceding tics. Relative frequency of occurrence of the various features are designated with 'o' and '+' marks. *This table was produced by Joseph Jankovic, MD at the Baylor College of Medicine.*

TREATING TS AND OTHER TIC DISORDERS

Frequently tics are mild, so treatment is not required. However, if tics are moderate to severe, they may need direct treatment. If associated conditions are present, it may be necessary to treat these first or concurrently as they are often more impairing than the tics themselves. In all cases, it is essential to educate the individual and others in his/her life about TS and provide appropriate support across all settings (school, work, home). In addition, if tics require treatment, behavioral therapy and medications are available. Below are suggestions for determining the best treatment and support, based on your patient's needs.

EDUCATION IS KEY FOR ALL CASES

If your patient is not bothered by his/her tics and does not see them as a problem:

- Offer education about tics and support resources, including the Tourette Association of America's contact information.
- Determine whether there are symptoms of associated conditions that may need to be addressed.

If your patient is only bothered by his/her tics because others ask about them or tease your patient:

- Provide education and resources to family members. It is important to emphasize that telling the patient to "stop ticcing" is not an effective strategy and is likely to cause significant frustration.
- You should acknowledge that some individuals will find tics to be annoying. Thus, suggesting strategies for managing this, such as having brief periods of physical separation, playing background music, wearing noise-cancelling headphones, etc., may be helpful.
- It can be very helpful to educate teachers and peers with a class presentation, or showing the HBO documentary, *I Have Tourette's But Tourette's Doesn't Have Me*. This video is available through the TAA at no cost. Other resources can be found at tourette.org.
- Follow up with your patient as needed.

If the main concern is that the patient’s tics are causing him/her to do poorly in school or create problems with concentration:

- Request direct input from the patient’s teachers about his/her academic performance and behavior in school.
- Screen for and, if present, treat ADHD.
- Consider educational assessments for associated learning difficulties.
- Discuss the role of educational plans (e.g., 504 Plan, IEP).
- Use of appropriate classroom accommodations can greatly improve the academic performance of students with tics.
- Refer ancillary services if appropriate.

TICS ARE MOST BOTHERSOME

If the patient is bothered by one or several tics:

- Behavioral and medication therapies may be helpful in managing tics, particularly when tics become problematic or interfere with daily life. Since every patient is different, it may take some time and patience to determine the most effective treatment approach.
- Screen for associated disorders that may impede the patient’s success in behavioral therapy, such as untreated ADHD or significant Oppositional Defiant Disorder (ODD).
- Determine whether certain therapies are feasible from a logistical perspective. Is there a provider available locally? Does the patient have transportation? Will the patient’s insurance cover the treatments?
- Refer behavioral therapy if the patient is a good candidate and it is feasible.



COMPREHENSIVE BEHAVIORAL INTERVENTION FOR TICS (CBIT)

Comprehensive Behavioral Intervention for Tics (CBIT, pronounced “see-bit”) is a behavioral, non-medicated treatment designed to teach a patient and his/her family a specific set of skills to reduce the overall frequency, intensity, and impact of motor and vocal tics. CBIT has two primary therapeutic components: habit reversal training (HRT) and function-based treatment (FBT). Many individuals report that their tics are worsened by anxiety and stress. Therefore, relaxation techniques are typically employed during CBIT to reduce overall anxiety, stress, and tension. The primary therapeutic activities used in CBIT are described in the table below.

CBIT COMPONENT	ACTIVITY	PURPOSE
HABIT REVERSAL TRAINING	Awareness Training	Teach patient to recognize tics and tic warning signs (such as a premonitory urge).
	Competing Response Training	Teach patient to interrupt tics using a specific behavior that is incompatible with the performance of the tic.
	Social Support	Teach family members to prompt and reinforce the use of habit reversal skills.
FUNCTION-BASED TREATMENT	Function-Based Assessment	Monitor for day-to-day tic worsening and identify specific places, activities, reactions, and mood states that worsen tics.
	Function-Based Intervention	Teach patient to make changes to his/her day-to-day routine to minimize the impact of tic exacerbations.
RELAXATION TRAINING	Progressive Muscle Relaxation & Diaphragmatic Breathing	Teach patient relaxation skills to minimize tension, stress, and anxiety, which can worsen tics in the short term.

CBIT SCHEDULE

CBIT typically involves 8-10 weekly one-hour treatment sessions, in conjunction with at-home practice of CBIT skills between sessions, with patients and their families. The technique should be administered by a professional trained in CBIT, such as a psychologist, social worker, occupational therapist, or a CBIT-trained medical professional. The Tourette Association of America maintains a list of CBIT-trained professionals around the country at tourette.org.

CBIT TRIALS

The effectiveness of CBIT is well established. The strongest evidence comes from two large, randomized, controlled trials (an adult trial and a child trial) comparing CBIT to supportive psychotherapy. Results from both trials showed that CBIT was associated with a significantly greater decrease in tic severity at post-treatment relative to the control group. In the child trial, 53% of children receiving CBIT were rated as treatment responders versus 19% in the control group; 87% of responders maintained treatment gains in a 6-month follow-up. In the adult trial, 38% of patients receiving CBIT were rated as treatment responders versus 6% in the control group; 80% of participants receiving CBIT maintained treatment gains in a 6-month post-treatment follow-up. The degree of symptom reduction was similar to what has been reported in medication trials.

WHAT CBIT DOES NOT ADDRESS

It is important to note that CBIT is specifically designed to reduce the severity and impact of motor and vocal tics. Although research shows that some patients might experience a modest improvement in other symptoms (e.g., anxiety, oppositionality) following CBIT, it is not designed to address the myriad of other psychiatric conditions and symptoms that commonly co-occur with tic disorders (e.g., ADHD, OCD, ODD, mood disturbance, or impulsivity). For these associated conditions, pharmacotherapy and/or empirically-based, disorder-specific psychotherapies (usually involving some form of CBT) are recommended.

MEDICATIONS FOR TICS

If the patient is bothered by multiple tics equally, has self-injurious tics, is not a good candidate for CBIT, or has failed a trial of CBIT, consider medication in lieu of or in addition to CBIT.

- Monitor the patient's progress on medications and adverse reactions if any.
- It is important to explain that medications may take some time to work. It may also take some trial and error to determine which medication (or combination of medications) works best for the patient as each patient will respond differently.
- Emphasize that medications are not cures and the tics may not completely resolve. The goal of treatment is to reduce tics to a point that they are no longer causing distress/interference with function. Tics still wax and wane in frequency and severity; fluctuations will continue to occur whether or not medication is used. Sometimes, what may seem to be an initial response to a medication may simply have been a coincidence if tics were beginning to wane at the same time the medication was introduced.



Haloperidol (Haldol), pimozide (Orap), and aripiprazole (Abilify) are currently the only medications approved by the U.S. Food and Drug Administration (FDA) to treat tics. However, physicians may start with “off-label” use (not FDA approved specifically for treatment of tics) of guanfacine or clonidine, both of which are alpha-adrenergic agonist medications that are approved for use in the treatment of high blood pressure. These medications have been found to be moderately effective in reducing tics and to be better tolerated. The Tourette Association maintains a list of physicians who are knowledgeable about these medications and who can provide consultation. The lists can be found at tourette.org.

Below is a flowchart of pharmacotherapy treatments to consider for treatment of tics.²

Alpha-2 Agonist
(guanfacine, guanfacine ER, Clonidine, Clonidine ER)

Mild tics or moderate tics with co-morbid obesity:
Topiramate

Moderate to severe tics:
Atypical antipsychotic
(aripiprazole, ziprasidone, risperidone, etc.)

Typical antipsychotic
(haloperidol, pimozide). **Need baseline EKG with pimozide.**
Avoid medications that increase QTc interval.
Perform genotyping on patients taking pimozide at doses of >4 mg/day.

Tetrabenazine, botulinum toxin

² Flowchart courtesy of the Tourette Association of America Medical Advisory Board

MEDICATIONS FOR CO-OCCURRING CONDITIONS

Co-occurring conditions, such as ADHD and OCD, often require medication, which can improve quality of life in patients with TS. It is not unusual for the treatment of these conditions to result in a reduction of tics. Inattention, impulsivity, and hyperactivity are common symptoms seen in patients with ADHD and can be an obstacle for school-aged children. Stimulant medications, such as methylphenidate, can be effective in children who have TS and ADHD. Other non-stimulant medications, such as guanfacine, clonidine, and atomoxetine, may also be beneficial.

Selective serotonin reuptake inhibitors (SSRIs), such as fluoxetine, sertraline, and fluvoxamine, are effective in youth and adults with anxiety/OCD. Side effects are generally tolerable. Be aware of the risks and benefits of these medications, and share this information with your patients and their families.

ANXIETY AND TICS

If the patient has moderate to severe anxiety and is bothered by his/her tics:

- Treat the patient's anxiety with Cognitive Behavior Therapy (CBT) or medications first.
- Then reassess the level of impairment from tics. If the tics are still impairing once the patient's anxiety is adequately controlled, you may want to consider CBIT or medications to treat the tics.

ADDITIONAL REHABILITATION AND ANCILLARY SERVICES

Psychology, Psychiatry and Neurology have traditionally been the primary sources of treatment for TS and Tic Disorders. However, more recently, other healthcare professionals have been collaborating with traditional disciplines and are recognized as important partners in treating co-occurring developmental conditions. Interdisciplinary clinics are being created to maximize the benefits of these ancillary services. These services can contribute to increase the quality of and diversify care for those with Tic Disorders:

- **Occupational Therapy (OT):** Therapy to enable participation in roles, habits, and routines in home, school, workplace, community, and other settings.
- **Physical Therapy (PT):** Therapy to restore, maintain, and promote physical function.
- **Speech-Language Pathology (SLP):** Treatment of speech, language, social communication, cognitive-communication, and swallowing disorders

Access to OT, PT, and SLP services may be more readily available in rural areas and can be used to treat co-occurring conditions. Therapists administering these types of services have the ability to address these associated conditions without specialty training in contrast to other types of therapists. Co-occurring conditions can be managed with the utilization of rehabilitation services and contribute to improving symptoms for those with TS or other Tic Disorders.

If your patients with tics struggle with any of the associated conditions listed above, then they may benefit from rehabilitation services. It is important to note that not all people who are affected with TS are affected by these associated conditions.

Questions to ask a rehabilitation facility or health care provider when determining an appropriate clinic for referral:

- Does your clinic offer interdisciplinary care with OT, PT, and SLP?
- What specialty training certification have you taken to advance your clinical skills?
- Do you have any training specifically tailored to treat patients with TS (or any of the co-occurring conditions that you are addressing)?
- Would you be interested in talking to someone and/or seeing some helpful resources from the Tourette Association of America to gain information about working with individuals with Tourette Syndrome?

	OT	PT	SLP
Executive Functioning	●		●
Sensory Integration	●		
Attention Training	●		
Pain Management		●	
Social Skills & Pragmatic	●		●
Activities of Daily Living	●		
Handwriting	●		
Sleep Hygiene	●		
Assistive Devices	●		
Stuttering			●
Pelvic Health Issues		●	
Incoordination	●	●	
Fine Motor	●		
Gross Motor		●	
Reading Comprehension			●
Dyslexia			●
Vocational Skills	●		●
Oculomotor or Vision	●		
Feeding Aversion	●		
Driving Readiness	●		
Arousal & Impulse Control	●		●

KEY ARTICLES REFLECTING THE CURRENT SCIENCE AND RESEARCH IN TOURETTE AND TIC DISORDERS

General / Prevalence

Bitsko, R. H., Holbrook, J. R., Visser, S. N., Mink, J. W., Zinner, S. H., Ghandour, R. M., & Blumberg, S. J. (2014). A National Profile of Tourette Syndrome, 2011-2012. *Journal of Developmental & Behavioral Pediatrics*, 35(5), 317-322. Study key findings: <http://www.cdc.gov/ncbddd/tourette/features/keyfinding-nationalprofile.html>

Leckman, J. F., Zhang H., Vitale A., Lahnin F., Lynch K., Bondi C. Kim Y., & Peterson B. S (1998). Course of Tic Severity in Tourette Syndrome: The First Two Decades. *Pediatrics*, 102(1), 14-9.

Scharf, J. M., Miller, L. L., Gauvin, C. A., Alabiso, J., Mathews, C. A., & Ben-Shlomo, Y. (2014). Population prevalence of Tourette syndrome: A systematic review and meta-analysis. *Movement Disorders Mov Disord.*, 30(2), 221-228.

Thenganatt, M. A., & Jankovic, J. (2016). *Recent Advances in Understanding and Managing Tourette Syndrome*. F1000Research F1000Res.

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Genetics / Associated Conditions

Hirschtritt, M. E., Lee, P. C., Pauls, D. L., Dion, Y., Grados, M. A., Illmann, C., . . . Mathews, C. A. (2015). Lifetime Prevalence, Age of Risk, and Genetic Relationships of Comorbid Psychiatric Disorders in Tourette Syndrome. *JAMA Psychiatry*, 72(4), 325.

CBIT

Piacentini, J., Woods, D. W., Scahill, L., Wilhelm, S., Peterson, A. L., Chang, S., . . . Walkup, J. T. (2010). Behavior Therapy for Children With Tourette Disorder. *Jama*, 303(19), 1929.

Wilhelm, S., Peterson, A. L., Piacentini, J., Woods, D. W., Deckersbach, T., Sukhodolsky, D. G., . . . Scahill, L. (2012). Randomized Trial of Behavior Therapy for Adults With Tourette Syndrome. *Arch Gen Psychiatry Archives of General Psychiatry*, 69(8), 795.

Pharmacotherapy

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Weisman, H., Qureshi, I. A., Leckman, J. F., Scahill, L., & Bloch, M. H. (2013). Systematic review: Pharmacological treatment of tic disorders – Efficacy of antipsychotic and alpha-2 adrenergic agonist agents. *Neuroscience & Biobehavioral Reviews*, 37(6), 1162-1171.

“The Spectrum of Tourette Syndrome and Tic Disorders: A Consensus by Scientific Advisors of the Tourette Association of America. This 2015 position paper is available on request from the Tourette Association of America.”

Quality of Life

Cavanna, A. E., David, K., Bandera, V., Termine, C., Balottin, U., Schrag, A., & Selai, C. (2013). Health-Related Quality of Life in Gilles de la Tourette Syndrome: A Decade of Research. *Behavioural Neurology*, 27(1), 83-93.



tourette.org 888-4TOURET

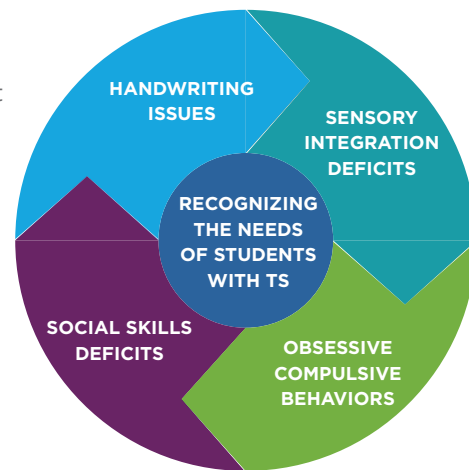


Addressing Your Patient's Education Needs



POTENTIAL IMPACT ON EDUCATION

Tourette Syndrome (TS) is difficult for some teachers to understand because every student has different tics that change, wax and wane, and are inconsistently managed. Teachers are not usually well-versed in strategies and techniques for recognizing the needs of students with TS or the most effective teaching approach. Besides the tics, there are many common co-occurring conditions that can be impairing, such as Attention Deficit/Hyperactivity Disorder (ADHD), handwriting difficulties, sensory integration or sensory processing disorders, obsessive-compulsive behaviors, and social skills deficits.



10 THINGS DOCTORS SHOULD KNOW ABOUT STUDENTS WITH TS AND EDUCATION ACCOMMODATIONS

1. **A DIAGNOSIS OF TS** does not mean that a child is automatically eligible for additional support from either a 504 Plan or an IEP. There is information on Tourette Association of America (TAA) website that assists parents with this complicated process.
2. It is not unusual for a child with TS to do well in lower grades because their intellect tends to overcome the related disorders, such as executive function deficits. **IN HIGHER GRADES, SCHOOL IS TYPICALLY MORE CHALLENGING** and disabilities may disguise intellectual abilities.
3. Students with TS generally **DO BETTER WITH SUPPORT IN GENERAL EDUCATION SETTING**.
4. Smaller settings tend to include students who have lower academic abilities and/or significant behavior issues, **WHICH MAY NOT BE A GOOD FIT FOR THE STUDENT'S LEARNING POTENTIAL**.
5. **WHEN CHILDREN MANAGE THEIR SYMPTOMS** better in the school setting and less at home, it often results in schools blaming the parents or assuming that the child is manipulating the family.
6. **BULLYING BY STUDENTS OR TEACHERS IS A VIOLATION OF CIVIL RIGHTS**. When not resolved, incidents can be reported to the local Office of Civil Rights.
7. Some of the **MOST COMMON SUPPORT TOOLS** are for handwriting (e.g., keyboard, notes provided, scribe), as many children with TS have handwriting difficulties.
8. Support in developing individualized strategies for **EXECUTIVE FUNCTION DEFICITS** are critical for students in grades 7-12.
9. There are Federal laws that protect students from being punished for their symptoms. Knowing and understanding this is critical to the **PROACTIVE PROCESS FOR ALL STUDENTS WITH TS**.
10. **ENCOURAGE PARENTS TO BECOME FAMILIAR** with the Resources & Support Page on the TAA website so they are prepared to access resources as needed.

EDUCATION RIGHTS

Obtaining a parent handbook from your State Department of Education or becoming familiar with the state website is extremely helpful and important in recognizing laws specific to your state. (More information about each state is available on the US Department of Education website at ed.gov/policy.)

The Individuals with Disabilities Education Act (IDEA) is a federal law that requires schools to provide special education services to meet the educational needs of eligible students with disabilities. **IDEA includes Tourette Syndrome under the definition of Other Health Impairment (OHI)**. Additionally, the Federal Department of Education states that Tourette Syndrome may require special education services and should not be confused with the needs of a student with behavioral or emotional disorders:

... we do believe that Tourette Syndrome is commonly misunderstood to be a behavioral or emotional condition, rather than a neurological condition. Therefore, including Tourette Syndrome in the definition of other health impairment may help correct the misperception of Tourette Syndrome as a behavioral or conduct disorder and prevent the misdiagnosis of their needs.³

504 PLANS & INDIVIDUALIZED EDUCATION PROGRAMS (IEPs)

Students with disabilities may require services provided by either a **504 Plan or Individualized Education Program (IEP)**.

504 protections and supports are part of the federal civil rights law. A 504 Plan typically provides modifications and accommodations for students who have symptoms that impede on that student's equal access to an education.

IEPs designate special education and related services to meet the unique needs of a student. They may include the same provisions of a 504 Plan.

Some important things to note:

- **Both** 504 Plans and IEPs are legal documents detailing a student's specific needs which must be implemented by school personnel. Teams, which include parents, determine if a student meets the specified requirements regarding eligibility for a 504 Plan or IEP.
- A TS diagnosis does not automatically qualify a student for a 504 Plan or IEP.
- Good grades do not disqualify a student from being eligible for 504 Plan or IEP.

Manifestation Determination is a federal law intended to ensure that students with 504 Plans or IEPs are not being punished for symptoms of their disabilities.



³ US Department of Education. Federal Regulations 300.8(c)(9), Comment Section.



Sample Doctor's Letter



Tourette Association of America

Awareness. Research. Support.

Sample Letter Requesting Initial Evaluations/Assessments for IEP or 504 Plan

Attention (Child's school)

Child's name was diagnosed with Tourette Syndrome (**list any related diagnoses**) on **Date**.

A diagnosis of Tourette Syndrome (TS) is complex. Every student with TS is unique and tics may change, as well as wax and wane, making this a difficult disorder to understand and manage. In addition to the motor/vocal tics, many common related disorders may impact a student's access to a well-rounded education.

In most cases, a student will require education evaluations to determine which of the related disorders may be impacting (**his/her**) education. Common difficulties that may occur in a child with TS, which I have not yet assessed in this child, include dysgraphia (written language deficits); Attention Deficit/Hyperactivity Disorder (ADHD), Anxiety, Sensory Integration, Social Communication Disorder, Processing Delays, Memory Deficits, Executive Function Deficits, and Obsessive-Compulsive Disorders. It is important that all teachers and support staff (with the permission from the parents) understand the complexities of this disorder so that (**Name**) is not inappropriately punished for symptoms, and so that the student can be proactively supported.

It is imperative that (**Name**) experiences school as an accepting and supportive environment. This may involve specific special education supports and accommodations. I would strongly suggest that you visit the Tourette Association of America (TAA) website (tourette.org) for detailed lists of accommodations and services.

I recommend that the school identify a designated individual to become knowledgeable about TS and make him/herself known to the student as a trusted support person. The Tourette Association is an excellent resource for parents and professionals. It is often helpful to have a team conference call with a member of the Tourette Association of America Education Advisory Board. The TAA can be reached at 888-4TOURET or at support@tourette.org.

Signature



Awareness. Research. Support.

tourette.org | 888-4TOURET

How can the Tourette Association Help?



COORDINATED CARE FOR TOURETTE & TIC DISORDERS

The Tourette Association of America's Center of Excellence (CofE) program aims to improve the quality of life of people with Tourette Syndrome and other Tic Disorders by promoting the highest level of care; research; education and training; and advocacy and awareness. The program, which was developed in collaboration with leading medical and scientific experts in Tourette and related conditions, was launched in 2014 with the initial designation of nine CofEs located at premier medical and academic institutions across the United States.

The Centers are collaborating with the Tourette Association and professional and lay communities to address many needs and concerns across the following key areas:

EXPERT & COORDINATED CARE

TAA CofEs provide timely and accurate evaluations of TS and related conditions. Thus, patients can receive coordinated care using evidence-based treatment and management approaches from multidisciplinary teams of care providers.

RESEARCH

TAA CofEs conduct or collaborate on scientific and clinical research studies within their own institutions or elsewhere. These investigations aim to provide a better understanding of TS/Tic Disorders, their impact, and to advance the development of more effective and safe treatments.

EDUCATION & TRAINING

TAA CofEs provide training and education to healthcare professionals and researchers on Tourette Syndrome, Tic and related disorders. These centers also help educate patients, families and the general public on these conditions.

ADVOCACY & AWARENESS

TAA CofEs work with the national Association and its local chapters and support groups to improve awareness and advocate for TS in their local communities and nationally.

CLINICAL SERVICES OFFERED AT CENTERS OF EXCELLENCE INCLUDE:

- Child and Adult Neurology and Psychiatry
- Allied Health Care Providers
- Evaluations, Diagnoses and Advice
- Medical Treatments
- Behavioral Therapies (e.g. CBIT/CBT)
- Counseling and Psychological services
- Occupational Therapy
- Deep Brain Stimulation (DBS)
- Botulinum Toxin Therapy



TOURETTE ASSOCIATION CENTERS OF EXCELLENCE CLINIC LOCATIONS

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: BAYLOR COLLEGE OF MEDICINE

Houston, TX
Director: Joseph Jankovic, M.D.
Co-Director: Suzanne Mouton-Odum, Ph.D.
(713) 798-2273

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: CHILDREN'S MERCY HOSPITAL

Kansas City, MO
Director: Keith Coffman, M.D.
Co-Director: James Batterson, M.D.
(816) 234-3674

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: THE JOHNS HOPKINS HOSPITAL

Baltimore, MD
Director: Harvey Singer, M.D.
Co-Director: Marcos Grados, M.D.
(410) 955-4259

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: MASSACHUSETTS GENERAL HOSPITAL

Boston, MA
Director - Jeremiah Scharf, M.D., Ph.D.
Co-Director: Sabine Wilhelm, Ph.D.
(617) 726-5532

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: NEW YORK STATE CONSORTIUM

Weill Cornell Medical College

New York, NY
Director: John Walkup, M.D.
Co-Director: Shannon Bennett, Ph.D.
(212) 821-0789

Northwell Health

Manhasset, NY
Director: Cathy Budman, M.D.
Co-Director: Jane Zwilling, Psy.D.
(516) 562-3051

University of Rochester Medical Center

Rochester, NY
Director: Jonathan Mink, M.D., Ph.D.
Co-Director: Heather Adams, Ph.D.
(585) 275-2808

Icahn School of Medicine at Mount Sinai

New York, NY
Director: Barbara Coffey, M.D.
Co-Director: Wayne Goodman, M.D.
(212) 659-1660

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: SOUTH EAST REGIONAL

Emory University School of Medicine

Atlanta, GA
Director: Jorge L. Juncos, M.D.
(404) 778-3444

University of Alabama at Birmingham

Birmingham, AL
Director: Leon Dure, M.D.
Co-Director: Jan Rowe, OTR/L, FAOTA
(205) 638-6820

University of Florida

Gainesville, FL
Director: Michael Okun, M.D.
Co-Director: Irene Malaty, M.D.
(352) 294-5400

Palmetto Health

Columbia, SC
Director: Rebecca Lehman, M.D.
(803) 434-7961

University of South Florida

St. Petersburg, FL
Director: Tanya Murphy, M.D.
Co-Director: Adam Lewin, Ph.D.
(727) 767-8230

Southeast CofE Coordinator
Heather Simpson, MOT, OTR/L
(352) 294-5385
simplh@shands.ufl.edu

Clinic website: www.TouretteCareCenters.org

TOURETTE ASSOCIATION CENTER OF EXCELLENCE: UNIVERSITY OF CALIFORNIA, LOS ANGELES

Los Angeles, CA
Director: John Piacentini, Ph.D.
Co-Director: James McCracken, M.D.
(310) 825-0122

CENTER OF EXCELLENCE: UNIVERSITY OF UTAH

Salt Lake City, UT
Director: Michael Himle, Ph.D.
Co-Director: Francis Filloux, M.D.
(801) 585-1086
Clinic website: www.TSUtah.info

TOURETTE ASSOCIATION CENTER CENTER OF EXCELLENCE: YALE CHILD STUDY CENTER

New Haven, CT
Director: Robert King, M.D.
Co-Director: Michael Bloch, M.D.
(203) 785-5880



Awareness. Research. Support.

tourette.org 888-4TOURET



Awareness. Research. Support.

TOURETTE ASSOCIATION OF AMERICA

Founded in 1972, the Tourette Association of America is dedicated to making life better for all individuals affected by Tourette and Tic Disorders. The Association is the premier nationwide organization serving this community, working to raise awareness, advance research and scientific understanding, and provide on-going support. The Tourette Association directs a network of 32 Chapters and more than 80 support groups across the country. For more information on Tourette and Tic Disorders, call **888-4TOURET**, visit **tourette.org**, and search “Tourette Association” on Facebook, Twitter, Instagram and YouTube.

REQUEST RESOURCES AND INFORMATION ON TOURETTE

In addition to the information provided on the Tourette Association website (**tourette.org**), the Tourette Association’s Information and Referral (I&R) team offers accurate, evidence-based information on Tourette Syndrome (TS), Tic Disorders, and related conditions to families, individuals, professionals, and the general public. You can request more information or speak with a TAA I&R staff member by calling **888-4TOURET** or email **support@tourette.org**.

LOCAL CHAPTERS OR SUPPORT GROUPS

Tourette Association of America Chapters and Affiliated Support Groups are groups of volunteers dedicated to supporting and promoting the mission of the Tourette Association of America in the community. Please visit **tourette.org** to find support in your area.

The following are some of the **services** that may be offered through the TAA Chapters and Support Groups:

- **CLIENT SERVICES:** Information and Referrals (I&R); telephone help-line; support groups (may be done in person, by phone or electronically); website and/or electronic discussion groups.
- **PUBLIC SERVICE:** Awareness activities; information/publications; education – presentations, conferences.
- **PROFESSIONAL EDUCATION:** In-service presentations for educators and allied professionals; resource services; Medical and Allied Professional (MAP) Referral Lists; presentations provided by the Tourette Health & Education Program, a program of the TAA Partnership with the US Centers for Disease Control and Prevention (CDC).
- **PUBLIC POLICY:** Partner with national organizations on public policy projects; meet with local representatives and government agencies to promote Tourette awareness and help lobby for legislation that helps the Tourette community.
- **PEER PROGRAMS:** Youth Ambassador Program; camps; socialization opportunities

You can view a complete list of and learn more about how to get involved with TAA’s Chapter and support groups by visiting [tourette.org/resources/find-local-chapter/](https://www.tourette.org/resources/find-local-chapter/). You can also email **support@tourette.org**, or call **888-4TOURET**.

TOURETTE ASSOCIATION YOUTH AMBASSADOR (YA) PROGRAM

The Tourette Association of America's Youth Ambassador Program trains teens to talk about Tourette and Tic Disorders, to advocate for themselves and for others, and to provide their peers and younger children with accurate information. Youth Ambassadors teach understanding, sensitivity, and tolerance of TS and its symptoms, while dispelling the myths and stereotypes that are often attributed to and associated with TS and other Tic Disorders. Through this program, young people can speak to peers at schools, sports leagues, camps, after school programs, and similar venues, as well as in front of local and national politicians. Youth Ambassadors play an important role in increasing awareness and understanding of Tourette Syndrome and Tic Disorders in the community.

For more information about the Youth Ambassador Program, to apply to be a Youth Ambassador, or request a Youth Ambassador presentation at your school or organization, please contact the Tourette Association.

RESEARCH AND MEDICAL PROGRAMS

The Tourette Association of America's Research and Medical Programs department have several established and developing initiatives that, together, seek to advance our understanding of Tourette Syndrome, facilitate the development of treatments, and improve care for individuals living with the disorder. These programs cover a wide range of treatment modalities and include the TAA Brain Tissue Program, which seeks to better understand TS brain changes; the TAA International Consortium for Genetics, which aims to identify chromosomes and genes that predispose people to TS; the TAA Neuroimaging Consortium, which aims to uncover the neural changes that underlie TS; and the TAA Behavioral Sciences Consortium, which is focused on disseminating and understanding the mechanisms of effective treatments like CBIT.

GET INVOLVED IN THE TOURETTE COMMUNITY

FOLLOW THE TOURETTE ASSOCIATION ON SOCIAL MEDIA

The Tourette Association of America is active on Facebook, Twitter, Instagram, YouTube and LinkedIn. Follow the Tourette Association for the latest news, stories, and updates.

Facebook @TouretteAssociation **Twitter @TouretteAssn**
Instagram @TouretteAssociation **YouTube @Tourette TV**

PARTICIPATE IN A TOURETTE HEALTH AND EDUCATION WEBINAR, #TOURETTECHAT

The Tourette Health and Education Program, a TAA partnership with the US Centers for Disease Control and Prevention (CDC), offers regular webinars, Twitter chats, and live streaming presentations on various topics related to Tourette and Tic Disorders. Each workshop features designated Tourette Experts who are members of the TAA medical, science, and education advisory boards.

MEDICAL AND ALLIED PROFESSIONAL REFERRAL LIST

If you are interested in or currently treating patients with Tourette or Tic Disorders, you can be included on our referral listing. For more information, please contact the Tourette Association.

BECOME A MEMBER

When you join the Tourette Association of America as a member, you play a critical role in making a difference and you join thousands of individuals, families, and professionals who are working to:

- Raise public awareness and foster social acceptance.
- Advance scientific understanding, treatment options, and care.
- Educate professionals to better serve the needs of children, adults and families.
- Advocate for public policies and services that promote positive school, work, and social environments.
- Provide help, hope, and a supportive community across the nation.
- Empower our community to deal with the complexities of this spectrum of disorders.

Visit tourette.org/membership for more information.

