

# FACTS ABOUT TOURETTE SYNDROME

## Answers to Most Commonly Asked Questions

### **What is Tourette Syndrome (TS)?**

TS is a child-onset complex neurological disorder characterized by tics – involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly. TS is often accompanied by obsessive-compulsive disorder (OCD); attention-deficit/hyperactivity disorder (ADHD); poor impulse control; and other behavioral issues. Although TS typically improves after adolescence, it may persist into adulthood and be a life-long condition. The severity of tics and co-morbid behavioral problems typically wax and wane over a period of time and can vary widely between individuals, with symptoms ranging from mild to disabling. Tics can sometimes be temporarily suppressed, but this requires mental effort and may be followed by a rebound worsening.

### **What are the most common symptoms?**

Commonly, motor tics consist of eye blinking, head jerking, shoulder shrugging, facial grimacing, and other jerk-like limb and body movements. Phonic (or vocal) tics are typically manifested by throat clearing, humming, barking noises, sniffing, and tongue clicking. Some patients make a variety of sounds and shout out utterances, including obscenities, called coprolalia (see below). Most patients describe sensation before each tic, referred to as a premonitory urge.

### **What is ADHD?**

Attention-deficit/hyperactivity disorder (ADHD) is characterized by the three primary symptoms of hyperactivity, impulsivity, and inattention. Some people with ADHD are predominately hyperactive and impulsive (e.g., can't sit still, always fidget, interrupt others, blurt things out or make inappropriate comments, difficulty waiting turn). Some with ADHD are predominately inattentive (e.g., make careless mistakes, have difficulty staying focused, difficulty following instructions or finishing things, are reluctant to do things that require mental effort, forgetful, daydream), and some people with ADHD demonstrate a combination of the two. Despite increased social awareness, these behaviors are often attributed to “lack of motivation,” “not trying hard enough,” or “poor parenting.”

### **What is OCD?**

Simply put, obsessive-compulsive disorder is characterized by the presence of obsessions and/or compulsions. Obsessions are intense, intrusive, repetitive thoughts such as concerns about evenness and neatness, unfounded or irrational fears (e.g. becoming ill, hurting someone/self, causing a flood or other catastrophe), perverse sexual thoughts, excessive concern about a body part, excessive concern with morality, intrusive words, phrases, music, or images. Compulsions are meaningless and/or irrational rituals such as checking, counting, cleaning, washing, touching, smelling, hoarding, and repeating. People with OCD often feel that something terrible will happen if they do not perform their compulsions. These symptoms can cause significant distress and often interfere with a patient's focus, concentration, and efficiency.

OCD symptoms include repetitive touching, tapping, a need for symmetry/evening up, and checking and re-checking. The obsessions (recurrent thoughts) and compulsions (repetitive behaviors) may lead to marked distress and dysfunction.

### **What is the cause of the syndrome?**

TS is thought to be due to an abnormally functioning basal ganglia, the portion of the brain deep inside the cerebral hemisphere that is most responsible for controlling the body's movement. Some studies suggest that abnormal regulation of the neurotransmitters such as dopamine and gabapentin reduces the ability of the basal ganglia to inhibit abnormal behavior. Unfortunately, the symptoms of many patients are wrongly attributed to “habits,” “allergies,” “asthma,” “dermatitis,” “hyperactivity,” “nervousness,” or many other conditions.

### **Is it inherited?**

While the exact cause is unknown, TS appears to be genetically inherited in the majority of individuals. Genetic studies indicate that TS is not due to a single gene mutation but results from complex interaction of many genes. Sons are three to four times more likely than daughters to exhibit clinical symptoms of TS.

### **Is obscene language (coprolalia) a typical symptom of TS?**

Although often overemphasized in lay and social media, the fact is that cursing, uttering obscenities, ethnic slurs, and obscene gestures are not manifested by all people with TS. These forbidden and socially unacceptable behaviors are often embarrassing and potentially expose the people with TS to bullying or other aggressions. New studies are being conducted on coprophobia, and the TAA MAB is in the process of publishing a white paper on this topic. For now, it is estimated that around 20% of children with TS have coprolalia.

### **How is TS diagnosed?**

Diagnosis is made by observing symptoms and evaluating the history of their onset. No blood analysis, X-ray, or other type of medical test can identify this condition.

### **How is it treated?**

Currently, there is no known cure for TS, but many safe and effective treatments are available to alleviate the symptoms. It is essential that the selection of the therapy is individualized and targeted to the most troublesome symptom. Therefore, a comprehensive evaluation by a Tourette expert is important, as symptoms associated with ADHD, OCD, or other behavioral difficulties may be more problematic than the tics. Tics usually improve with drugs that block or deplete dopamine or in some cases with injections of botulinum toxin into the abnormally contracting muscles causing focal tics. Tics can sometimes be managed with Comprehensive Behavioral Intervention for Tics (CBIT), a non-pharmaceutical recommended treatment. Central stimulants and drugs that act on the adrenaline system are useful in the treatment of ADHD, and Cognitive Behavioral Therapy (CBT) may also be helpful. Serotonin receptor blocking drugs and other medications are often effective in treating symptoms of OCD as well as anxiety and mood abnormalities. Individuals react differently to the various medications, and frequently it takes some time until the right substance and dosage for each person are achieved. In addition, appropriate accommodations at school, tutoring, counseling, and other interventions may be helpful in addressing academic, emotional, social, and behavioral problems that arise as a result of the impact of TS, OCD, and ADHD on their daily lives.

### **Is there a remission?**

Many people with TS will improve, not worsen, as they mature, especially after adolescence. In a small minority of cases, symptoms will remit completely in adulthood, but others may recur later in life.

### **Do children with TS have special educational needs?**

As a group, children with TS have a higher incidence of academic or artistic giftedness than the population at large. However, many also have difficulty demonstrating their abilities due to an increased incidence of learning issues, often associated with the level of severity of the symptoms and comorbidities of ADHD, OCD. Problems dealing with the tics, often combined with ADHD, OCD, and other learning issues, may necessitate special education (OHI) or 504 assistance.

### **How many people are affected?**

Tourette Syndrome and other Tic Disorders are not rare. The current estimates are that 1 out of every 160 children between the ages of 5-17 years in the United States has TS and that 1 out of every 50 children has TS or another persistent Tic Disorder. All ethnic groups are similarly affected.

### **What is the prognosis?**

In general, people with TS lead productive lives and can anticipate a normal life span. Despite problems of varying severity, many reach high levels of achievement and number in their ranks as surgeons, psychiatrists, teachers, executives, professional musicians, and athletes.

### **What is the Tourette Association of America – Texas Chapter?**

The Tourette Association of America (TAA) is the only national voluntary health organization dedicated to identifying the cause, finding the cure, and controlling the effects of this disorder. Its programs of research, professional and public education, and individual and family services are made possible through the generosity of donors. The Tourette Association of America – Texas Chapter partners with TAA. Tourette Texas, one of the largest chapters in the country, is a 501(c)3 non-profit organization. We raise funding to assist area families and children in crisis, 24 hours a day, 365 days a year.

#### **Tourette Association of America – Texas Chapter**

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