

# FACTS ABOUT TOURETTE SYNDROME

## Answers to Most Commonly Asked Questions

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

It is a 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 (AD/HD), poor impulse control, and other behavioral problems. TS typically begins in childhood and can vary between patients, with symptoms ranging from mild to disabling. Also, people with TS often find that their own symptoms fluctuate in severity and frequency over the course of their childhood. Tics can often be suppressed for periods of time, but this may cause discomfort and fatigue.

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

Commonly, motor tics may be eye blinking, head jerking, shoulder shrugging, facial grimacing. Vocally—throat clearing, barking noises, sniffing and tongue clicking. Symptoms change periodically in number, frequency, type and severity—even disappearing for weeks or months at a time.

### **What is AD/HD?**

Attention-deficit/hyperactivity disorder (AD/HD) is characterized by the three primary symptoms of hyperactivity, impulsivity, and inattention. There are three “types” of AD/HD. Some patients with AD/HD are predominantly hyperactive and impulsive (e.g. can’t sit still, always fidget, interrupt others, blurt things out or make inappropriate comments, difficulty waiting turn). Some patients with AD/HD are predominantly 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). Some patients with AD/HD 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”. If not properly treated, symptoms of AD/HD can significantly interfere with a patient’s academic/occupational, social, and emotional functioning.

### **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.

### **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 hemispheres that is most responsible for controlling the body’s movement. Some studies suggest that abnormal regulation of the neurotransmitter dopamine reduces the ability of the basal ganglia to inhibit 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 patients. Genetic studies indicate that TS is inherited as a dominant gene, with about 50% chance of passing the gene from parent to child. Sons are three to four times more likely than daughters to exhibit TS.

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

Definitely not. The fact is that cursing, uttering obscenities, and ethnic slurs are manifested by fewer than 15% of people with TS. Too often, however, the media seize upon this symptom for its sensational effect.

### **Do outbursts of personal ethnic and other slurs by people with TS reflect their true feelings?**

Quite the contrary. The very rare use of ethnic slurs stems from an uncontrollable urge to voice the forbidden even when it is directly opposite to the actual beliefs of the person voicing it.

### **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. The TS symptoms usually emerge between 5 and 18 years of age.

### **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 is important, as symptoms associated with AD/HD, OCD, or other behavioral difficulties may be more problematic than the tics. Tics usually improve with drugs that block or deplete dopamine or injections with botulinum toxin. Central stimulants, atomoxetine, and drugs that act on the adrenaline system are useful in the treatment of ADHD, impulse control and other behavioral symptoms. Serotonin receptor blocking drugs and other medications are often effective in treating symptoms of OCD. Individuals react differently to the various medications, and frequently it takes some time until the right substance and dosage for each person are achieved. Almost all of the medications prescribed for TS treatment do not have a specific FDA indication for the disorder. In addition, tutoring, psychotherapy, 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 AD/HD on patients' daily lives.

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

Many people with TS get better, not worse, as they mature. In a small minority of cases symptoms remit completely in adulthood.

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

As a group, children with TS have the same IQ range as the population at large. But problems in dealing with tics, often combined with attention-deficit disorder, obsessive-compulsive disorder and other learning issues may call for special education assistance. Examples of teaching strategies include: technical help such as tape recorders, typewriters or computers to assist reading and writing and access to tutoring in a resource room.

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

Since many people with TS have yet to be diagnosed, there are no absolute figures. The official estimate by the National Institutes of Health is that 200,000 Americans have full-blown TS. Some genetic studies suggest that the incidence may be as high as one in two hundred if those with chronic multiple tics and/or transient childhood tics are included in the count. Other studies suggest this figure may be significantly higher.

### **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 and professional musicians and athletes.

### **What is the Tourette Syndrome Association?**

TSA is the only national voluntary health organization dedicated to identify 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 Syndrome Association of Texas partners with the national Tourette Syndrome Association. TSA of TX, one of the largest chapters in the country, is a 501(c)3 non-profit organization. We raise funds to assist area families and children in crisis, 24 hours a day, 365 days a year.

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