

TOURETTE SYNDROME

What it is and What it is not

Tourette Syndrome (TS) is a neurological disorder that begins in childhood characterized by tics - involuntary, rapid, sudden movements that occur repeatedly in the same way. The tics may occur many times a day nearly every day or intermittently. Tics periodically change in number and frequency, type and location and wax and wane in their severity. While some persons with TS have limited control of their symptoms from seconds to hours at a time, suppressing them may merely postpone more severe outbursts. Tics increase as a result of stress anxiety, excitement and fatigue. They often decrease with relaxation or concentration on a absorbing task.

WHAT IT IS

TS is characterized by motor and vocal tics. A motor tic is an involuntary, rapid, sudden movement that occurs repeatedly.

Examples of motor tics might include but are not limited to: eye-blinking; shoulder-shrugging; head-jerking; finger-tapping; facial grimaces.

A vocal tic is a sound, noise, word, or group of words that is meaningless or out of context. Common examples of vocal tics are: sniffing; throat-clearing; squealing; barking.

Coprolalia is the most infamous and problematic type of vocal tic. It refers to the involuntary utterance of curse words, ethnic or racial slurs, or socially inappropriate phrases or sentences, often with sexual connotations. These may be quite elaborate in nature and, therefore, misinterpreted as intentional utterances. Coprolalia is not necessary for a diagnosis of TS.

Both motor and vocal tics tend to "wax and wane" in response to environmental factors. Tics may change in frequency, type, and

location over time. Environmental factors that make tics worse include stress anxiety, excitement, fatigue and illness.

The symptoms of TS may worsen during puberty and may improve after the adolescent years. TS is a chronic, lifelong disorder.

At present, there is no medical test to prove or disprove the presence of TS and the carrier gene or genes have not yet been identified. Below are the criteria that physicians use to diagnose TS:

1. Multiple motor and one or more vocal tics present for at least one year although not necessarily simultaneously.

2. The occurrence of tics many times a day (usually in bouts) nearly every day or intermittently throughout a span of more than one year.

3. Periodic changes in the number, frequency, severity, type, and location of the tics. Symptoms can sometimes disappear for weeks or months at a time.

4. Onset before the age of 18 years but most typically between the ages of 6 and 8 years.

WHAT IT IS NOT

People with TS are not emotionally disturbed and are not dangerous.

- TS is primarily a neurological disorder. Although there are sometimes problems associated with TS (anxiety, depression), people with TS are not crazy.

- People with TS are not mentally retarded.

- People with TS reflect the general population, although their intelligence is skewed slightly toward the superior end of the spectrum.

- You cannot catch TS and you cannot die from TS.

- TS is a genetic disorder that is not life threatening.

- Children with TS are responsible for their actions.

- Children with TS must be helped to take responsibility for their own behavior and not be punished for it. Children with TS are not responsible for their medical disorder, but are responsible for its impact on other people.

- Children with TS do not manifest the same symptoms, or severity of symptoms, all the time.

- The disorder waxes and wanes over time. People with neurological impairments, such as TS, manifest a wide variability in functioning from hour to hour. Things are always changing.

- Tics cannot always be clearly differentiated from behaviors.

- TS is far more than tics. Tics and associated behaviors seem to merge and are difficult to separate.

- Disorganization and impulsivity in not willful.

- Often children with TS manifest symptoms of ADHD. This is an associated disorder and the symptoms are not willful.

- People with TS do not always swear. Actually, only about 10 percent of people with TS demonstrate Coprolalia (which means they swear.)

- Medication will not cure TS.

- Medications can help with some of the symptoms, sometime...but they do not generally suppress the wide range of symptoms associated with TS.

- People with TS cannot control the symptoms if they want to.

- The fact that some people can control the symptoms some of the time confuses everyone. ■

Thanks to the Tourette Syndrome Association of Greater Washington (TSAGW) for this fact sheet. For more information, please visit the website www.tsagw.org or call 877-295-2148 (Toll free) or 301-681-4133.