TOURETTE SYNDROME

Patient Information Fact Sheet

>What is Tourette syndrome?

Tourette syndrome is a fairly rare, inherited neurological condition named after French physician George Gilles de la Tourette, who described the syndrome in the 1800s. Usually, Tourette syndrome presents before the age of 18. Although the exact prevalence is unknown because many cases go undiagnosed, Tourette syndrome is thought to affect up to one in every 100 school children and is three to four times more common in males than in females. The official estimate by the National Institutes of Health is that about 100,000 Americans have full-blown Tourette syndrome. The condition occurs in people from all ethnic groups.

Tourette syndrome is characterized by multiple involuntary movements (tics) and uncontrollable vocal sounds. In some people, coprolalia (uttering socially inappropriate words and phrases) is also present. In some cases of Tourette syndrome, the symptoms disappear spontaneously after adolescence. In most cases multiple tics and vocal symptoms continue into adulthood, although they may become less of a problem. In a small proportion of cases symptoms become more severe in adulthood.

>What causes Tourette syndrome?

The exact cause of Tourette syndrome is not clear, although recent research suggests that an abnormality relating to the metabolism of dopamine, a chemical found in the brain, may be involved. A person with Tourette syndrome has roughly a 50% chance of passing it on to his or her child. The condition may be expressed in the child in different ways, for example, as chronic multiple tics or as obsessive-compulsive symptoms. The risk of passing on the condition is three to four times greater for a son than a daughter.

>What are the symptoms of Tourette syndrome?

The symptoms vary greatly from person to person and range from mild to severe. However, most people have mild symptoms and are able to lead normal lives and work in a variety of professions. Involuntary movements (tics) are rapid, repetitive movements of individual muscle groups which are not intentional and serve no purpose. They include blinking of the eyes, grimacing, squinting and sometimes vocalizations such as humming. They usually last a few weeks or months and are not the result of behavioral problems, although they usually occur at times of excitement or fatigue. Transient tic disorders usually begin during early childhood and often disappear within a year or so. Around a quarter of children are affected by simple tics. Sometimes these tics may persist into adulthood (chronic simple tics). Chronic tic disorders are characterized by their unchanging nature and can persist for years. The term 'chronic multiple tics' indicates that a person has several different unchanging motor tics.

Tourette syndrome tends to be the most debilitating tic disorder and the person usually suffers from several, constantly changing tics. The symptoms can be motor, vocal or behavioral. Motor tics can be simple movements such as jaw snapping and eye blinking or complex actions such as hopping, clapping and touching people or things. Some complex actions seem to be compulsive in their need for repetition, for example, going over a letter so many times that the paper wears thin.



Simple vocal tics can include hissing, coughing or barking. Complex vocal tics can involve phrases that interfere with normal speech, sudden slurring of speech, an accent, or inappropriate emphasis on a word. The most distressing symptom of Tourette syndrome is coprolalia, where foul or "dirty" words are used during normal speech. The language may include sexual or racial insults, which are not intended to offend but appear suddenly in speech. Although coprolalia affects fewer than 15% of people with Tourette syndrome, a common misconception is that all sufferers display this symptom.

Some people may also have a tendency to mimic another person's actions or repeat their own speech or sounds involuntarily. The frequency of tics varies greatly. Some people are able to suppress their symptoms while at school or work, but this often means that the tics will then occur at a distressing level once the person reaches home. If the tics are multiple and severe, they may occur constantly while the person is awake. Besides the problems caused by the physical movements, problems such as social isolation may also arise. The symptoms can cause social embarrassment and vocational or academic failure.

In some people Tourette syndrome may be accompanied by behavioral problems, such as: obsessive-compulsive behavior; manic depressive disorders; schizoid behavior; phobic disorders; autism and Asperger's syndrome; sexual disorders; learning disorders and dyslexia; alcoholism; or eating disorders.

>How is Tourette syndrome treated?

Most people with Tourette syndrome are able to manage without medication. If there are accompanying behavioral problems, one-to-one teaching, counseling and other forms of individual help are all beneficial. If non-drug treatment is not successful and the symptoms of Tourette syndrome are disabling, then medication may be advised. Neuroleptic drugs such as haloperidol or pimozide (Orap) may be prescribed. In some patients other types of medicine such as clonidine (Kapvay) and tetrabenazine (Xenazine) are effective. In patients with obsessive-compulsive symptoms treatment with drugs such as fluoxetine (Prozac), clomipramine (Anafranil), or sertraline (Zoloft) may be helpful. Furthermore, tricyclic antidepressants may be utilized in addition to the following stimulants: methylphenidate (Ritalin) or dextroamphetamine (Dexedrine). The medication should be given in the lowest possible dose needed to suppress the worst of the symptoms. The person may have to tolerate less disabling symptoms—for example, an eye tic is more tolerable than coprolalia. Symptoms may vary over time and if they diminish, the medication should also be altered accordingly. For severe tics, a long-acting (depot) injection of haloperidol (Haldol Decanoate Injection) may be prescribed.

>Further information

National Tourette Syndrome Association: www.tsa-usa.org

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