# What you should know about Tourette Syndrome

# What is Tourette Syndrome?

Tourette Syndrome (TS) is a chronic, neurological behavioral disorder characterized by tics-quick, involuntary movements that occur repeatedly and wax and wane in frequency. Tourette Syndrome begins in childhood and sometimes requires lifelong treatment.

The symptoms include:

- Multiple motor and one or more vocal tics occurring at some time during the course of the disorder, although not necessarily at the same time;
- The presence of tics many times a day (usually in bouts). Tics can occur nearly every day or sporadically for more than one year;
- Periodic changes in the number, frequency, type and location of the tics, and in waxing and waning of their severity. Sometimes symptoms mysteriously disappear for weeks or months at a time.

The onset of these symptoms typically occurs before age 18. However, TS usually emerges between the ages of 2 and 15.

Although the term "involuntary" is used to describe tics, some people with TS do have some control over their symptoms. However, this control, which can be exerted from seconds to hours at a time, only delays more severe tic outbursts. Movements are as irresistible as the urge to sneeze or scratch a mosquito bite, and must eventually be expressed. People with TS often delay the release of their symptoms until after school or work so that they can experience them when unobserved. Tics usually increase as a result of tension or stress and decrease with relaxation or concentration on a specific task.

# How are "tics" classified?

Tics are classified as motor and vocal, and simple and complex, although the boundaries of these are not well defined.

- Simple motor tics include eye blinking, neck jerking, shoulder shrugging and facial grimacing.
- Complex motor tics include facial gestures, groaning behaviors, hitting or biting oneself, jumping, touching stamping and smelling.
- Simple vocal tics include coughing, throat clearing, grunting, sniffing, snorting and barking.
- Complex vocal tics include repeating words or phrases out of context, coprolalia (the rare use of foul language), palilalia (increasingly rapid repetition of a phrase or word (and echolalia (repetition of words).

It has been estimated that up to 3% of all children exhibit tics at some time, but for many, they are transient and simply disappear with time. When the symptoms include the four categories previously mentioned and persist for more than one year, a diagnosis of TS can be considered.

## What are the early signs of Tourette Syndrome?

Early signs of TS may involve tics of the eye, most commonly eye blinking. Other common early signs include tics of the head and face. Repeated throat clearing is another common early symptom, as are such complex movements as touching, leg and arm thrusting and jumping.

#### What causes Tourette Syndrome?

The cause of TS is not yet clearly understood. Research findings suggest that TS may result from a malfunction of one or more neurotransmitter systems in the brain. There is also a genetic component to TS, and considerable research efforts are directed toward finding genes that cause the disorder. A person with TS has about a 50% chance of passing the gene to his or her children. However, not all those who inherit the TS genetic predisposition will have symptoms sever enough to warrant medical attention.

#### What other behavior patterns are associated with Tourette Syndrome?

People with TS may suffer from any number of the following behaviors:

- Obsessive-compulsive traits
- Hyperactivity
- Attention deficit disorder (ADD)
- Learning disabilities
- Self-injury
- Antisocial behavior
- Inappropriate sexual behavior
- Anger outbursts
- Discipline problems
- Sleep problems

It is important to note, however, that with TS, these behavior can wax and wane, just as the motor and vocal tics of this disorder.

#### How is Tourette Syndrome diagnosed?

No medical tests exist to confirm a diagnosis of TS. Diagnosis is made strictly by observation of symptoms, a thorough patient history and family recounting events and behaviors of the patient. Tracking the occurrence of the classic TS symptoms mentioned earlier in this leaflet helps to establish an accurate diagnosis.

#### Does Tourette Syndrome get better or worse?

Although it is clear that TS is a lifelong illness, as people with TS mature, there is a reduction of symptoms. Some investigators have noted a waxing and waning of symptoms throughout life. Others have found that remission – complete or incomplete-occurs in the late teens or early twenties. No matter what the pattern, some patients with TS do require lifelong treatment.

#### What can be done for patients with Tourette Syndrome?

While there is not yet a cure, there are various treatments that are available to help patients cope with their symptoms. Early diagnosis and treatment of TS are most important. Treatment may include both psychological and drug interventions, as well as effectively counseling the family of the patient. Most patients have such mild symptoms that an accurate diagnosis, an explanation of symptoms and some booklets on the subject are all that are needed to alleviate the fears and concerns often associated with having the disorder. For those with more pronounced symptoms, there are drugs available to effectively manage and help treat both the motor and vocal tics. Many find that medication greatly alleviates their symptoms. However, medication needs to be administered carefully and in small doses to obtain the greatest benefit with the least number and degree of side effects. Any questions or concerns you may have about medication can be answered by your physician or pharmacist.

Supportive counseling is vitally important in helping both the TS patient and his or her family. The Tourette Syndrome Associated can help by providing information and group support to patients and families and through its program of promoting research on Tourette Syndrome.

## Where can I get more information?

Consult your doctor or call/write:

Tourette Syndrome Association, Inc. 42-40 Bell Boulevard Bayside, JY 11361 Tel: (718) 224-2999 Fax: (718) 279-9596 Visit the web site at www.tsa-usa.org

About Tourette Syndrome:

It is estimated that about 200,000 people in this country have been diagnosed with Tourette Syndrome. First described in 1825 by Dr. Georges Gilles de la Tourette and later named after him, this disorder is often underdiagnosed. Prompt and effective diagnosis and treatment are the keys to appropriate management of Tourette Syndrome. Information and group support are often helpful for both patients and family members so that they can all live easier with Tourette Syndrome.

This information in this brochure is provided as a service to patients and their families by:

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