

## 1 Q. What is Tourette Syndrome?

**A.** Tourette Syndrome (TS) is a neurological disorder characterized by tics—involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. The symptoms include:

1. Both multiple motor and one or more vocal tics present at some time during the illness 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; and

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

4. Onset before the age of 18.

The term "involuntary" used to describe TS tics is sometimes confusing since it is known that most people with TS do have some control over their symptoms. What is not recognized is that the control, which can be exercised anywhere from seconds to hours at a time, may merely postpone more severe outbursts of symptoms. Tics are experienced as irresistible and (as with the urge to sneeze) eventually must be expressed. People with TS often seek a secluded spot to release their symptoms after delaying them in school or at work. Typically, tics increase as a result of tension or stress, and decrease with relaxation or when focusing on an absorbing task.

TS is not degenerative; intelligence and life span are no different from that of the general population.

## 2 Q. How would a typical case of TS be described?

**A.** The term typical cannot be applied to TS. The expression of symptoms covers a spectrum from very mild, to quite severe. However, the majority of cases can be categorized as mild.

## 3 Q. Is obscene language (coprolalia) a typical symptom of TS?

**A.** 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.

## 4 Q. What causes the symptoms?

**A.** The cause has not been established, although current research presents considerable evidence that the disorder stems from the abnormal metabolism of at least one brain chemical (neurotransmitter) called dopamine. Undoubtedly, other neurotransmitters, e.g. serotonin, are involved as well.

## 5 Q. How is TS diagnosed?

**A.** A diagnosis is made by observing symptoms and by evaluating the history of their onset. No blood analysis or other type of neurological testing exists to diagnose TS. However, some physicians may wish to order an EEG, MRI, CAT scan, or certain blood tests to rule out other ailments that might be confused with TS. Rating scales are available for assessment of tic severity.

## 6 Q. What are the first symptoms?

**A.** The most common first symptom is a facial tic such as rapidly blinking eyes or twitches of the mouth. However, involuntary sounds, such as throat clearing and sniffing, or tics of the limbs may be the initial signs. For a minority, the disorder begins abruptly with multiple symptoms of movements and sounds.

## 7 Q. How are tics classified?

**A.** Two categories of TS tics and several other examples are:

### Simple:

Motor — Eye blinking, head jerking, shoulder shrugging and facial grimacing.

Vocal — Throat clearing, yelping and other noises, sniffing and tongue clicking.

### Complex:

Motor — Jumping, touching other people or things, smelling, twirling about and, only rarely, self-injurious actions including hitting or biting oneself.

Vocal — Uttering words or phrases out of context and rarely, coprolalia (vocalizing socially unacceptable words).

The range of tics or tic-like symptoms that can be seen in TS is very broad. The complexity of some symptoms is often perplexing to family members, friends, teachers and employers who may find it hard to believe that the actions or vocal utterances are involuntary.



### Q. How is TS treated?

**A.** The majority of people with TS are not significantly disabled by their tics or behavioral symptoms, and therefore do not require medication. However, there are medications available to help control the symptoms when they interfere with functioning. The drugs include haloperidol (Haldol), clonidine (Catapres), pimozide (Orap), fluphenazine (Prolixin, Permitil), and clonazepam (Klonopin). Stimulants such as Ritalin, Cylert, and Dexedrine that are prescribed for ADHD may increase tics. Their use is controversial. For obsessive compulsive traits that interfere significantly with daily functioning, fluoxetine (Prozac), clomipramine (Anafranil), sertraline (Zoloft), risperidone (Risperdal) and paroxetine (Paxil) are prescribed.

Dosages which achieve maximum control of symptoms vary for each patient and must be gauged carefully by a doctor. The medicine is administered in small doses with gradual increases to the point where there is maximum alleviation of symptoms with minimal side effects. Some of the undesirable reactions to medications are weight gain, muscular rigidity, fatigue, motor restlessness and social withdrawal, some of which can be reduced with specific medications. Side effects such as depression and cognitive impairment may be alleviated with dosage reduction or a change of medication.

Other types of therapy may also be helpful. Psychotherapy can assist a person with TS and help his/her family cope, and some behavior therapies can teach the substitution of one tic for another that is more acceptable. The use of relaxation techniques and/or biofeedback can serve to alleviate stress reactions that cause tics to increase.



### Q. Is it important to treat Tourette Syndrome early?

**A.** Yes, especially in those instances when the symptoms are viewed by some people as bizarre, disruptive and frightening. Sometimes TS symptoms provoke ridicule and rejection by peers, neighbors, teachers and even casual observers. Parents may be overwhelmed by the strangeness of their child's behavior. The child may be threatened, excluded from activities and prevented from enjoying normal interpersonal relationships. These difficulties may become greater during adolescence—an especially trying period for young people and even more so for a person coping with a neurological problem. To avoid psychological harm, early diagnosis and treatment are crucial. Moreover, in more serious cases, it is possible to control many of the symptoms with medication.



### Q. Do all people with TS have associated behaviors in addition to tics?

**A.** No, but many do have one or more additional problems which may include:

**Obsessions** which consist of repetitive unwanted or bothersome thoughts.

**Compulsions and Ritualistic Behaviors** which occur when a person feels that something must be done over and over and/or in a certain way. Examples include touching an object with one hand after touching it with the other hand to "even things up" or repeatedly checking to see that the stove is turned off. Children sometimes beg their parents to repeat a sentence many times until it "sounds right."

**Attention Deficit Disorder with or without Hyperactivity (ADD or ADHD)** occurs in many people with TS. Children may show signs of hyperactivity before TS symptoms appear. Indications of ADHD may include: difficulty with concentration; failing to finish what is started; not listening; being easily distracted; often acting before thinking; shifting constantly from one activity to another; needing a great deal of supervision; and general fidgeting. Adults too may exhibit signs of ADHD such as overly impulsive behavior and concentration difficulties and the need to move constantly. ADD without hyperactivity includes all of the above symptoms except for the high level of activity. As children with ADHD mature, the need to move is more likely to be expressed by restless, fidgety behavior. Difficulties with concentration and poor impulse control persist.

**Learning disabilities** like reading and writing difficulties, arithmetic disorders and perceptual problems.

**Difficulties with impulse control** which may result, in rare instances, in overly aggressive behaviors or socially inappropriate acts. Also, defiant and angry behaviors can occur.

**Sleep disorders** are fairly common among people with TS. These include frequent awakenings or walking or talking in one's sleep.



### Q. Do students with TS have special educational needs?

**A.** While school children with TS as a group have the same IQ range as the population at large, many have special educational needs. Data show that many may have some kind of learning problem. That condition, combined with attention deficits and the difficulty coping with frequent tics, often call for special educational assistance. The use of tape recorders, typewriters, or

computers for reading and writing problems, untimed exams (in a private room if vocal tics are a problem), and permission to leave the classroom when tics become overwhelming are often helpful. Some children need extra help such as access to tutoring in a resource room.

When difficulties in school cannot be resolved, an educational evaluation may be needed. A resulting identification as "other health impaired" under federal law will entitle the student to an Individual Education Plan (IEP) which addresses specific educational problems in school. Such an approach can significantly reduce the learning difficulties that prevent the young person from performing at his/her potential. The child who cannot be adequately educated in a public school with special services geared to his/her individual needs may be best served by enrollment in a special school.

**12 Q. Is TS inherited?**

**A.** Genetic studies indicate that TS is inherited as a dominant gene that causes varying symptoms in different family members. A person with TS has about a 50% chance with each separate pregnancy of passing the gene to one of his/her children. However, that genetic predisposition may express itself as TS, as a milder tic disorder or as obsessive compulsive symptoms with no tics at all. It is known that a higher than normal incidence of milder tic disorders and obsessive compulsive behaviors occur in the families of those with a TS diagnosis.

The sex of the offspring also influences the expression of the gene. The chance that the gene-carrying child of a person with TS will have symptoms is at least three to four times higher for a son than for a daughter. Yet only about 10% of the children who inherit the gene will have symptoms severe enough to ever require medical attention. In some cases TS may not be inherited, and cases such as these are identified as sporadic TS. The cause in these instances is unknown.

**13 Q. Is there a cure?**

**A.** Not yet.

**14 Q. Is there ever a remission?**

**A.** Many people experience marked improvement in their late teens or early twenties. Most people with TS get better, not worse, as they mature, and those diagnosed with TS can anticipate a normal life span. As many as 1/3 of patients experience remission of tic symptoms in adulthood.

**15 Q. How many people in the U.S. have TS?**

**A.** 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 100,000 Americans have full-blown TS. Some genetic studies suggest that the figure 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.

**16 Q. What is the history of TS?**

**A.** In 1825 the first case of TS was reported in medical literature with a description of the Marquise de Dampierre, a noblewoman whose symptoms included involuntary tics of many parts of her body and various vocalizations including coprolalia and echolalia. Later, Dr. Georges Gillés de la Tourette, the French neurologist for whom the disorder is named, first described nine cases in 1885. Samuel Johnson, the lexicographer, and André Malraux, the French author, are among the famous people who are thought to have had TS.

**17 Q. What is the current focus of research?**

**A.** Since 1984, the TSA has directly funded important research investigations in a number of scientific areas relevant to TS. Recently, studies have intensified to understand how the disorder is transmitted from one generation to the next, and researchers are working toward locating the gene marker for TS. That focus has been enhanced by the efforts of a TSA-supported international group of scientists who have formed a unique network to share what they know about the genetics of TS and to systematically cooperate to unravel the unknown. Additional insights are being obtained from studies of large families (kindreds) with numerous members who have TS. At the same time, investigators continue to study specific groups of brain chemicals to better understand the syndrome and to identify new and improved medications.

**18 Q. What types of services for families exist?**

**A.** Local TSA affiliates and support groups allow families to exchange ideas and feelings about their common problems. Often family therapy is helpful. Parents of a child with TS have to walk a fine line between understanding and overprotection. They are constantly faced with deciding whether or not certain actions are the expression of TS or just poor behavior. Parents then must determine the appropriate response. For socially unacceptable behavior, a child should be encouraged to control what he/she can whenever possible, and to try to substitute what is more socially

acceptable. Parents are urged to give their children with TS the opportunity for as much independence as possible, while gently but firmly limiting attempts by some children to use their symptoms to control those around them.



### Q. What is the Tourette Syndrome Association?

A. TSA, founded in 1972, is the only national voluntary non-profit membership organization dedicated to:

- Identifying the cause;
- Finding the cure; and
- Controlling the effects of TS.

Members include individuals with the disorder, their relatives and other interested, concerned people. The Association develops and disseminates educational material to individuals, professionals and to agencies in the fields of health care, education and government; coordinates support services to help people and their families cope with the problems that occur with TS; funds research that will ultimately find the cause of and cure for TS and, at the same time, lead to improved medications and treatments.

#### TSA also:

- Offers direct help to TS families in crisis situations through its Information and Referral Service
- Organizes workshops and symposiums for scientists, clinicians and others working in the field of TS
- Promotes public awareness and understanding
- Maintains a database of allied professionals
- Sponsors the Tourette Syndrome Brain Bank Program involving collection of sorely needed tissue for scientific research
- Serves many thousands of members throughout the USA and abroad
- Increases the knowledge and sensitivity of health care professionals to TS through exhibits at conferences, the dissemination of literature and the organization of national meetings
- Develops and maintains state-by-state lists of doctors who can diagnose and treat TS
- Organizes and assists local chapters and support groups throughout the US and around the world
- Represents the interests of members to the government on critical policy issues including orphan drugs, health insurance and employment



### Q. Why become a member of TSA?

- A. — To help reduce stigma by supporting TSA in its efforts to increase public understanding of TS symptoms
- To help bring about the early identification and proper treatment of TS
  - To receive the quarterly TSA Newsletter containing the latest information on treatment, research programs and scientific discoveries
  - To join other families at meetings to discuss common problems and offer mutual support
  - To obtain discounts on videotapes and publications
  - To support TSA advocacy programs
  - To become eligible for discounted registration fees at TSA National Conferences.
- **To help conquer Tourette Syndrome**

The Tourette Syndrome Association, Inc. has an extensive list of publications and video tapes that discuss in detail many of the topics touched upon in this pamphlet. Full descriptions are contained in the *TSA Catalog of Publications and Films*. **Write for a free copy.**

This brochure is intended to provide basic information about TS. It is not intended to, nor does it constitute medical advice. Readers are warned against changing medical schedules or life activities based on this information without first consulting a physician.

Our programs of research, professional and public education, and family services are made possible through the generosity of our donors.

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