

# Questions and Answers about Tourette Syndrome

## What is Tourette Syndrome?

Tourette Syndrome (TS) is a neurological disorder which most often begins between the ages of 2 and 21, and lasts throughout life. TS is NOT degenerative, and people with TS can expect to live a normal life span.

## What are the symptoms?

TS is characterised by rapid, repetitive and involuntary muscle movements and vocalisations called “tics”, and often involves behavioural difficulties. The term “involuntary”, used to describe tics, is a source of confusion since it is known that most people with TS do have some control over their symptoms. What is often not recognised is that the control, which can be exerted from seconds to hours at a time, only delays more severe outbursts of symptoms. Tics are experienced as irresistible and eventually must be performed. Typically, tics increase as a result of tension or stress and decrease with relaxation or concentration on an absorbing task. TS symptoms have long been misconstrued as a sign of behavioural abnormality or “nervous habits”, which they are not.

## How are tics classified?

The two categories of the tics of TS and some common examples are:

### SIMPLE:

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

**Vocal**—Throat-clearing, barking, squealing, sniffing, gulping, grunting, and tongue clicking.

### COMPLEX:

**Motor**—Jumping, touching other people or things, twirling about, repetitive movements of the torso or limbs, and self-injurious actions including hitting or biting oneself.

**Vocal**—Uttering words or phrases, coprolalia

(the involuntary utterance of inappropriate or obscene words), palilalia (repetition of their own words), echolalia (repeating a sound, words or phrase just heard).

The variety and complexity of tics or tic-like symptoms that can be seen in TS is enormous.

## Do people with TS have all of these symptoms, or just some of them?

People with TS rarely have all of these symptoms. Most people will exhibit some or many symptoms over a long period of time, and in varying degrees; mild, moderate or severe. In milder cases a person may have just a few tics or twitches which may be confined to the face, eye and shoulder areas. In more severe cases several areas of the body may be affected. The symptoms wax and wane, in some cases from day to day but usually over 3 to 4 month periods. The waxing and waning pattern can sometimes be frightening to people with TS who may find it difficult to understand the sudden intensification or waning of symptoms.

## Are there other behaviour problems which may occur frequently in addition to tics?

Yes, but not always. Additional problems may include:

**Obsessive Compulsive Disorder**—in which the person feels that something must be done over and over. Examples include touching an object with one hand after touching with the other hand to “even things out” and repeatedly checking to see that the flame on the stove is turned off. Children sometimes beg their parents to repeat a sentence or phrase many times until it “sounds right”. OCD can include counting rituals and obsessive thoughts which are unpleasant.

**Attention Deficit (Hyperactivity) Disorder**—in children may include: difficulty in concentrating, being easily distractible, failing to finish tasks, acting on impulse, not seeming to listen, shifting constantly from one activity to another, needing a great deal of supervision, unable to sit still. Adults may have residual signs

of ADD such as overly impulsive behaviour and concentration difficulties.

**Learning Disabilities**—such as dyslexia, arithmetic and perceptual difficulties, poor hand-writing.

**Behavioural Problems**—may include compulsive and repetitive behaviours, attention problems, sleep disorders, depression, poor self-esteem, poor school performance, social isolation, school and social phobia. In severe forms, oppositional and defiant behaviours, aggressive and uncooperative behaviours are seen.

## What are the first symptoms?

The most common first symptom is a facial tic such as rapidly blinking eyes or twitching of the mouth. However, involuntary sounds, such as throat clearing and sniffing, or tics of the limbs may be the initial sign. In some cases childhood behaviour difficulties precede tics.

## What causes the symptoms?

The major cause has not been definitely 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 are also involved.

## Is it inherited?

Studies suggest that TS is inherited as a dominant gene that may produce different symptoms in different family members. A person with TS has about a 50% chance of passing the gene to one of his/her children. However, that gene may be expressed as TS, as a milder tic disorder, as ADHD or obsessive compulsive symptoms with no tics at all. For many, the gene is not expressed and remains silent with no recognisable disorder or symptoms. It is accepted that a higher than normal incidence of mild tics, ADHD and obsessive compulsive behaviours occur in families with TS. Some cases of TS have no obvious familial history and are identified as “sporadic” TS, as the cause is unknown.

## Can people with TS delay or suppress their symptoms?

Postponement or substitution of TS symptoms is a skill that some people are able to master. It requires considerable energy and concentration to inhibit vocalisations or motor movements for even a few minutes. Family members, teachers and co-workers must be understanding and compassionate when this cannot be accomplished. To avoid embarrassment and ridicule in certain social situations, some children and adults with TS often try to inhibit their symptoms. However, symptoms may emerge more explosively when they arrive home or are able to shelter themselves in private surroundings where they feel more comfortable. This phenomenon can create a diagnostic problem for physicians, who often do not observe tic symptoms during examination.

## Is TS a psychiatric disorder?

No, it is a neurological disorder. However, secondary psychological problems, e.g. depression, may arise from persistent difficulties in coping with the disorder and society’s reaction to its unique symptoms. Some behavioural difficulties which may be a part of the syndrome i.e. poor attention span, compulsiveness, aggressive outbursts, can also cause significant adjustment problems. In some cases, psychological counselling may be needed to help a person with TS adjust, help him/her to build coping skills, and come to terms with TS.

## How is TS diagnosed?

The diagnosis is made by observing the symptoms and by evaluating the history of their onset. No blood analysis, x-ray, or other type of medical test exists to identify TS. However, a doctor may wish to order an EEG, Cat Scan, or certain blood tests to rule out other ailments that could be confused with TS.

## Is there a cure?

Not yet, but medication can be effective to control some of the symptoms in some cases.

**Can people with TS lead normal lives?**

They certainly can, and the great majority do. People with TS do not become less intelligent. Many reach high achievement in the areas of academia, business and sportsmanship.

**Is there ever a remission?**

Some people experience periods where the symptoms seem to disappear; others experience a marked improvement in their late teens or early twenties.

**How would a typical case of TS be described?**

The term typical cannot be applied to TS. The expression of symptoms covers a spectrum from very mild to very severe and TS is an individual and complex disorder.

**How is TS treated?**

There are several drugs which can reduce the symptoms of TS for many people. Unless symptoms substantially interfere with a person's life, medication may not be necessary. None of the medication presently available for treatment of TS will entirely eliminate all symptoms. Instead, symptoms may be reduced, sometimes substantially, but they will continue to wax and wane, and they will commonly appear more pronounced during stressful periods.

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

While children with TS as a group have the same IQ range as the population at large, many have special educational needs. It is estimated that many may have some kind of learning problem. That condition combined with attention deficits and the problem inherent in dealing with frequent tics, may call for special educational assistance.

**Is it important to treat TS early?**

Yes, when the symptoms of the condition are viewed by some people as bizarre and disruptive, frequently TS may provoke ridicule and rejection by peers, neighbours, teachers,

and even casual observers. Parents may be overwhelmed by the strangeness of their child's behaviour. The child may be threatened, excluded from family 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. The opportunity for parents and young people to gain mutual support can be very important. TS is not well known, but as more doctors become aware of the symptoms, undiagnosed cases are likely to decrease in the future.

**How many people have TS?**

We don't know for sure but estimates are around 1 in every 100 boys and 1 in every 300 girls.

**How did Tourette Syndrome get its name?**

Dr George Gilles de la Tourette (1857-1904) was a neurologist living in France. He was the first to identify the syndrome by giving a description of the Marquise de la Dampierre, a noble woman whose symptoms included coprolalia. She lived to the age of 86.

**What is the Tourette Syndrome Association of Australia and what does it do?**

TSAA is a largely voluntary and non-profit organisation consisting of people with TS, and their families, professional and other interested and concerned individuals. The Association disseminates educational materials in the fields of health care, education, and welfare services; provides telephone counselling and operates support groups. We provide parent advocacy and other services to help families cope with problems that may occur with TS. The Association regularly publishes newsletters. We continue to work towards seeking better treatments and improving the overall quality of life for TS sufferers.

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- Further information on Tourette Syndrome
- Information on how I can join TSAA
- Please find enclosed my tax deductible donation to "Tourette Syndrome Association" to assist your efforts to help people affected by Tourette Syndrome
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*The TSAA is an Incorporated Charity and GST exempt*

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