

# Tourette Syndrome



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## What is Tourette syndrome?

Tourette Syndrome (TS) is a neurological disorder; this means it affects the nervous system. It is characterised by repetitive, stereotyped, involuntary movements and vocalisations called tics. The disorder was named after Dr George Gilles de la Tourette the pioneering French neurologist who in 1885 first diagnosed the condition in an 86-year-old French noblewoman.

The early symptoms of TS are almost always present, but not always noticed. TS is often un-diagnosed (or mis-diagnosed). The average onset is between the ages of 7 and 10 years. TS occurs in people from all ethnic groups although it is now thought there is an exception to this in Sub-Saharan Africa where TS might be rare. Males are affected by TS about 3 to 4 times more often than females. While TS can be a chronic condition with symptoms lasting a lifetime, most people with the condition experience their worst symptoms in their early teens, with improvements occurring in their late teens and continuing into early adulthood.

## What are the symptoms?

Tics are classified as either simple or complex. Simple motor tics are sudden, brief, repetitive movements that involve a limited number of muscle groups. Example include:

- Eye blinking
- Head jerking
- Shoulder shrugging
- Facial grimacing

Simple vocalisations may include:

- Throat clearing

- Yelping and other noises
- Sniffing
- Tongue clicking

Complex tics are distinct, coordinated patterns of movement involving several muscle groups. Examples of complex motor tics include:

- Jumping
- Touching other people and things
- Smelling
- Twirling about

Complex vocal tics include:

- Uttering words or phrases out of context
- Coprolalia (vocalising socially unacceptable words)
- Echolalia (repeating a sound, word or phrase just heard)

Tics are often worse with excitement or anxiety and better during calm, focused activities. Certain physical experiences can trigger or worsen tics, for example a tight collar might trigger a neck tic. Tics do not go away during sleep but they are usually significantly diminished.

## What disorders are associated with TS?

Many people with TS experience additional neurobehavioral problems including:

- Inattention
- Hyperactivity
- Impulsivity
- ADHD

- Related problems with reading, writing and arithmetic
- Obsessive-compulsive symptoms such as intrusive thoughts or worries

All young people with TS need a tolerant and compassionate setting during Scouting that both encourages them to participate to their full potential and is flexible enough to accommodate their special needs. This means continuing to run an active balanced programme with challenging and engaging activities. A discussion with the parents of the young person should enable them to highlight any specific difficulties their child is likely to have and you can reflect this in programme planning.

#### **Other Useful Information**

- Many people with TS are able to suppress tics for a short time. The tics will eventually have to come out and suppressing them can feel uncomfortable and make it difficult to concentrate on other things. To understand how this might feel, people without TS can try not blinking for a while or holding their breath.
- Tics can wax and wane and change from day to day. Children with TS might have periods where they have no tics at all. There is no way of predicting the type and severity of tics a child may have, but it can be helpful to look at tics they have had in the past and how they have worsened/lessened through periods of stress/relaxation
- Tics can be suggestible: it is commonly reported that people with TS can pick up tics from other people they meet with TS.
- It can be useful to think of tics as the tip of the iceberg, when it comes to TS. Only 12% of people with TS have tics alone. Associated disorders such as OCD and ADHD can be more challenging.
- In addition to the associated disorders mentioned in this fact sheet, some people with TS also experience sleep disorders, rage attacks, self-injurious behaviour, depression, anxiety, inappropriate

sexualised behaviour and non-obscene socially inappropriate behaviour

- People with TS have the same range of IQ as the rest of the population.
- TS is thought to affect 1 in 100 school children.
- The average age for worst symptoms is 11.
- There is no cure, but there are medications available, some of which can have severe side-effects.
- Tics that could place children at particularly increased risk include touching sharp or hot objects, or hitting themselves or others.
- Certain food additives are thought to aggravate tics. Preliminary studies have suggested that caffeine and theine containing drinks such as coke, coffee and black tea as well as preserving agents, refined sugar and sweeteners may make tics worse.

#### **For further information:**

##### **Tourette Syndrome (UK) Association**

Helpline 0845 458 1252

[www.tsa.org.uk](http://www.tsa.org.uk)

##### **National Institute of Neurological Disorders**

[www.ninds.nih.gov/disorders/tourette/detail\\_tourette.htm](http://www.ninds.nih.gov/disorders/tourette/detail_tourette.htm)

Or contact the Special Needs office at Gilwell Park [special.needs@scout.org.uk](mailto:special.needs@scout.org.uk)