



Leader Support Guide

TOURETTE SYNDROME

1. What is it?

Tourette Syndrome is a hereditary neurological disorder characterised by sudden involuntary movements and vocal outbursts, that occur repeatedly in the same way. It is thought to affect 1: 2000, and is more common in boys than girls in a ratio of 4 to 1. It is believed that many children with behavioural difficulties have undiagnosed Tourette Syndrome. The tics are apparent before the age of twenty-one, more usually by the age of fifteen. The onset is typically between the ages of five to nine. Tics vary in frequency and severity, and both motor and vocal tics will be present at some stage, though not necessarily at the same time.

Parents and teachers often ignore the first symptoms, such as exaggerated eye-blinking, twitches of the mouth, or the 'hair out of eyes' movement. However, irritating mannerisms that are not Tourette Syndrome tend to disappear. Tourette Syndrome tics become exaggerated, or move to different parts of the body. Vocal tics or involuntary sounds such as throat clearing are almost always Tourette Syndrome. If a teacher is concerned about a child's tics it may help to encourage parents to see their GP, with a letter from the school to GP. The diagnosis is made by observing the symptoms, and taking a detailed history of their onset. There is no test.

2. IMPLICATIONS

People with Tourette Syndrome will have motor or vocal tics of some sort.

Common motor tics include -

- eye blinking or rolling
- head-jerking,
- shoulder shrugging and
- facial grimacing or squinting
- jumping, twirling about,
- making socially unacceptable gestures
- imitating the actions of others.

Common vocal tics include:-

- throat clearing, or yelping and other noises
- sniffing and tongue-clicking.
- uttering words or phrases out of context
- repeating own or others' words
- repeating the last word or phrase in a sentence
- using unacceptable or obscene language.

The people with Tourette Syndrome may –

- be quick tempered
- over-react in certain situations
- challenge authority
- have difficulties with organisation
- be unable to take turns when speaking
- **Take part in risky activities and be unaware of possible consequences**

Although tics are very difficult to control, the majority of those with Tourette Syndrome are not significantly disabled and do not require medication. However, there are associated conditions which include Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive and Ritualistic behaviours, anxieties, and difficulties with Impulse Control, which may require medication.

3. STRATEGIES

- Do not draw attention to the tics.
- Allow the youth member to leave the room ("time-out") when tics become overwhelming.
- Provide a quiet safe place where the youth member can release tics.
- Where tics interfere with speech allow the youth member to record answers or tape in private.
- Ensure that the youth member isn't being bullied or teased
- Recognise that there may be a neurological reason for behaviour and symptoms.

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