



Great Ormond Street Hospital for Children NHS Foundation Trust: Information for Young People

# An introduction to Tourette syndrome

This information sheet explains some basic facts about Tourette Syndrome (TS). It forms part of our TS information pack for young people and families.

## What is Tourette syndrome?

Tourette syndrome (TS) is a neurological (brain) condition. The main signs of TS are motor and vocal tics. Motor tics can be repeated movements, such as shoulder shrugs or touching things. Vocal tics can include repeated sounds, such as throat clearing or making a specific noise. Coprolalia, or saying rude words or swearing, is perhaps the most well known sign of TS but in fact only affects a small number of children with TS.

At best, a child or young person will only have some control over his or her tics. While he or she may be able to 'hold them in' for a while, it may be very difficult for them to do this for extended periods of time.

## How is TS diagnosed?

There are no specific tests used to diagnose TS. Diagnosis is made through observation and history taking. There are some standards for diagnosing TS, agreed internationally, as follows:

A child or young person must:

- Have multiple motor and one or more vocal tics that happen regularly although not necessarily at the same time.
- Have tics occurring many times a day or on and off for longer than one year. There should not have been a tic-free period of more than three months.
- Be distressed about the tics or they have a significant effect on home life, social life and schooling.
- Be less than 18 years old.
- Not have any other conditions that could cause the tics.

Although there is some discussion about these standards, most doctors use them as a guide for diagnosing TS.

## How common is TS?

TS was first described in the 19<sup>th</sup> Century by a neurologist, Gilles de la Tourette, after whom the condition is named. The symptoms can range from mild to severe. In the UK, it is thought to affect about one per cent of the population. We know that it affects more boys than girls, although we do not yet know why. It affects all races and ethnic groups equally.

## Are any other conditions seen alongside TS?

TS is associated with other conditions:

- Attention deficit hyperactivity disorder (ADHD)
- Obsessive compulsive disorder (OCD) and other anxiety disorders
- Anger or rage attacks
- Learning difficulties
- Depression

Please see our separate information sheets on these conditions for more information.

## How is TS treated?

It is important to get a confirmed diagnosis of TS before treatment starts. Referral is usually to a paediatrician (specialist children's doctor) or a child and adolescent psychiatrist in the first instance.

There is no specific treatment for TS, but aspects of the syndrome may benefit from treatment. Once the young person, their family, friends and school

understand about TS, they can usually cope well and no specific treatments may be needed.

Some of the difficulties in TS can be helped with medicines. These include the tics themselves, ADHD, OCD and sometimes depression. The combination of medicines varies from person to person. More information about these medicines is available in our other information sheets.

Behavioural therapies may be helpful in devising ways to manage tics or to help with anxiety or anger management. Talking therapies can also be helpful, in identifying triggers and patterns of tics which may reduce tics if changed themselves. Specific psychological treatment with cognitive behaviour therapy (CBT) may be useful for OCD or depression. Psychological approaches can also help family members to cope better with the stresses that living with a person with TS can bring.

## Where can I find more information about TS?

If you have a specific question or concern, talk to a member of the TS team.

The following book may be helpful:

**Uttom Chowdhury and Tara Murphy (2016)**

**Tic Disorders:** A Guide for Parents

and Professionals

Jessica Kingsley Publishers.

ISBN: 978-1-84905-061-6

The following organisation may also be able to offer support and advice:

**Tourettes Action**

Helpline: 0845 458 1252

Monday to Friday from 9am to 5pm

Web: [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk)