

Tourette Syndrome information sheet and key strategies

What is Tourette Syndrome?

Tourette syndrome (TS) is a multiple tic disorder that presents as motor and vocal tics. TS begins in childhood and waxes and wanes in its intensity and manifestations. In some, the tics may not be noticed, while in others, the tics can be quite disturbing and embarrassing for the young person and can be disruptive for normal classroom activities. Many people with TS can have a considerable decrease in their tics during adulthood, which may even halt completely.

A 'tic' can be described as a brief repetitive, involuntary (although can sometimes be suppressed or triggered) purposeless movement or sound. Tics tend to occur in bouts. Those that produce movement are called 'motor tics' and those that produce sounds are called 'vocal (phonic) tics' (GOSH NHS Foundation Trust, 2016)

- TS usually starts during childhood, but the tics and other symptoms usually improve after several years and sometimes go away completely.
- There's no cure for TS, but treatment can help manage symptoms.
- Some people with TS may also have other needs such as Obsessive Compulsive Disorder (OCD), Attention Deficit Hyperactivity Disorder (ADHD) or learning difficulties.
- Tics are the main symptom of TS. They may be worse during periods of stress, anxiety and tiredness. The range of tics is very broad, as illustrated in the **table below**.
- People with TS can have difficulty with emotion regulation and inhibiting behaviour (NHS website, <https://www.nhs.uk/conditions/tourettes-syndrome/>).

Most people with TS experience a strong urge before a tic, which has been compared to the feeling you get before needing to itch or sneeze. These feelings are known as **premonitory sensations**. Premonitory sensations are only relieved after the tic has been carried out. Examples of premonitory sensations include a burning feeling in the eyes before blinking, a dry or sore throat before grunting, an itchy joint or muscle before jerking, etc.

Table 1. showing 'simple' versus 'complex' motor and vocal tics

	Motor tics	Vocal tics
Simple	Eye blinking Eye rolling Grimacing Shoulder shrugging Limb and head jerking Abdominal tensing	Whistling Throat clearing Sniffing Coughing Tongue clicking Grunting Animal sounds
Complex	Jumping Twirling Touching objects and other people Obscene movements or gestures (copropraxia) Repeating other people's gestures (echopraxia)	Uttering words or phrases out of context Saying socially unacceptable words (coprolalia) Repeating a sound, word or phrase (echolalia)

(<https://www.tourettes-action.org.uk/19-symptoms-.html>)

How can TS affect learning and well-being?

Approximately **1% of school children** have TS (Robertson, 2008). TS is not a learning difficulty but some of the symptoms and co-occurring needs can have a substantial impact on a child's ability to learn. For example:

- Many children and young people with TS will try to suppress their tics at school. This takes a lot of effort and concentration which can compromise attention and ability to focus on school work.
- Writing can be made difficult by movement tics, or rigidity relating to how things should be written.
- Movement tics involving eyes can make reading tasks very difficult, while vocal tics can make reading aloud a source of anxiety and embarrassment.
- Difficulty with behaviour inhibition can manifest as calling out or speaking out of turn in class.
- Children with Tourette Syndrome may be at risk of bullying because their tics might single them out.
- Certain tics can be disruptive and distracting. It's important to note that tics are not always visible, for example people can experience internal tics such as stomach clenching and thought tics.
- Co-occurring needs may also affect learning in different ways.

Tourette Syndrome support strategies and approaches

- ❖ **Whole school awareness** – Provide training/awareness session to staff and to pupils so that there is a common understanding about TS.
- ❖ **Positioning in classroom** - Consider avoiding seating the pupil where his/her tics may be embarrassing or distracting to others, e.g. seating at the front.
- ❖ **Allow breaks** - If the pupil is showing an increase in tics, allow him/her to have a short break. The pupil can be given a 'time-out' pass to use when needed.
- ❖ **Extra support** - Be aware of the interference of tics with the child's learning activities and the energy it takes to try and suppress them – he/she may need extra support to catch up on any learning missed.
- ❖ **Provide a private, safe space for tics** - As much as possible, allow the child to experience his/her tics. Suppressing tics may increase anxiety and use up energy. A private space may be useful where the pupil can go to experience their tics.
- ❖ **Peer understanding** - Be sensitive to any peer reactions to tics and to possible teasing or misunderstandings.
- ❖ **Avoid responding to tics** - As much as possible, try to ignore tics and not draw any unnecessary attention to them. This demonstrates acceptance and normalises Tourette Syndrome and other related needs. Modeling acceptance can reduce both bullying and stress and may help the student with TS to focus his/her energy on academics rather than tic suppression. Punishment for tics is not appropriate as the pupil cannot always control them.
- ❖ **Handwriting** - Tics can make handwriting difficult so try not to put too much emphasis on good handwriting. Adjustments may support the pupil, e.g. the use of a computer, tablet, a scribe, or having notes provided.
- ❖ **Home and school communication** - Effective and clear communication between home and school is essential. Bear in mind that symptoms may differ in different environments
- ❖ **Teach a replacement behaviour** - This has been found to be useful in some cases.
- ❖ **Allow fiddle toys** - These can give pupils a focus on something may decrease his/her tics.
- ❖ **Give the pupil time and space** - Be patient when waiting for their responses.
- **Help the pupil to have an answer** - Some people find it easier to have a ready-made answer to questions about their tics. This is something a trusted adult can support the pupil to come up with.

References and resources

Chowdhury, U. & Murphy, T., (2016). *Tic Disorders: A Guide for Parents and Professionals*

Packer, L.E., & Pruitt S.K., (2010). *Challenging Kids, Challenged Teachers: Teaching Students with Tourette's, Bipolar Disorder, Executive Dysfunction, OCD, AD/HD and More*

Leaflet by GOSH NHS 'Tourette syndrome and managing tics in the classroom, 2016'

NHS website, 2018., <https://www.nhs.uk/conditions/tourettes-syndrome/>

Tourette's action https://www.tourettes-action.org.uk/storage/downloads/1473075007_tourettes-action-key-facts-for-teachers-Sep2016.pdf

<https://www.tourettes-action.org.uk/76-support-in-school.html>

<https://www.tourettes-action.org.uk/62-advice-for-teachers.html>

<https://www.tourettes-action.org.uk/67-what-is-ts.html>

Great Ormond Street Hospital <https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-treat/tourette-syndrome>