

Tourette Syndrome

Overview

Tourette Syndrome, also known as Tourette's or TS, is a neurological difference. Around one in every one hundred school children have Tourette's (Tourette's Action, 2023). The most common Tourette's trait is 'tics', these are involuntary sounds and movements. Although tics are not harmful to an individual's overall health, some physical tics can cause pain, such as "jerking of the head" (NHS, 2021). The frequency of tics can increase if an individual is stressed, tired or is feeling anxious. The cause of Tourette's remains unknown (NHS, Tourette's syndrome, 2021).

Types of Tics:

Motor Tics: Movements of the body. E.g., blinking, shrugging shoulders, jerking an arm

Vocal Tics: Sounds an individual makes with their voice. E.g., humming, clearing their throat, shouting out words or phrases

Simple Tics: Simple tics involve one or few body parts. E.g., sniffing

Complex Tics: Complex tics involve a number of body parts. E.g., bobbing the head while jerking an arm and making sounds.

Reference: (CDC, 2023)

Reducing tics

Students with Tourette's do not need to be 'treated'. However, it can be very physically and emotionally training for some students due to the amount of energy tics can use. Below are some suggestions of how to reduce tics:

- Some have found that activities that use a high level of energy, such as sports, or playing an instrument, can help reduce tics as the energy is being released in a different way.
- Reducing levels of stress and anxiety can also help reduce tics, the best way to support this will depend on the individual's preference. Some people find music relaxing, others might prefer going for a walk.
- Having a safe, quiet space for students to go if they're struggling with the number of tics they are having might reduce the levels of stress the student is experiencing and allow them to calm down.
- Ensuring staff and students are educated about Tourette's so the student can feel accepted and understood in the school/college community might help to reduce a student's anxiety around having tics in school/college. Trying to suppress tics can sometimes make them worse.

Reference: (Tourettes Action, 2023)

What can educational settings do to support students with Tourette's?

Students with Tourette's might experience a wide range of emotions as a result of their difference. Providing a safe space where students don't feel they have to suppress their tics could help to reduce anxiety and worries about attending school/college. In the first instance it's important to sit down with the student, their trusted adult in their setting and their trusted adult at home to discuss helpful ways to support them in their setting.

All of the following should be discussed with each individual student. Every student is different and therefore needs to be given the opportunity to share what works for them.

- Seating the student somewhere they are comfortable. Near the door for a quick exit and an area with larger personal space might be beneficial
- Providing students with a '*Time out*' card to allow them some time outside of the classroom or in a safe space when students are struggling with their tics.
- Creating a safe space where student can relax and no longer feel they need to suppress their tics. Ideally this room would have soft furnishings to ensure students are physically safe but also be somewhere students feel comfortable making loud noises.
- Encouraging teaching staff to ignore tics will help to normalise them and also reduce the attention on the student
- Remove unnecessary objects from desks to ensure the students safety and that of those around them
- Provide students with a fidget toy and help focus their movement
- Break down expected work into shorter more manageable tasks to allow students to deal with their tics and not feel behind with work.
- Allow students to use a laptop in lessons if they are able to type more effectively than write with their tics in mind
- Sometimes allow students to complete tests orally might be necessary to ensure the student is even an equal chance to show their capabilities
- Encourage students to engage with activities they enjoy that could help to reduce stress (e.g. music or sports)
- Provide students with an opportunity for physical movement throughout lessons (e.g. handing out books)
- Ensure all staff and students are made aware that the student has limited control of their tics
- Create an outline of behaviour expectations that the student and family agree with. This might look different to other students as a result of the stress, frustration and exhaustion that the student may experience
- Some students might find organisation, planning and remembering things difficult as a result of their Tourette's. Ensure students are given the support they would like to support them with this

(NHS, 2016)(NCCD, 2022)

Sources:

[https://media.gosh.nhs.uk/documents/Tourette and managing tics F0798 A4 bw FINAL Oct16 1.pdf](https://media.gosh.nhs.uk/documents/Tourette_and_managing_tics_F0798_A4_bw_FINAL_Oct16_1.pdf)

<https://www.nccd.edu.au/professional-learning/classroom-adjustments-tourette-syndrome>

<https://senmagazine.co.uk/content/specific-needs/tourettes/87/how-to-manage-tourettes-in-the-classroom/>

Bibliography

CDC. (2023, May 31). *What is Tourette Syndrome?* Retrieved from Centers of Disease Control and Prevention: <https://www.cdc.gov/ncbddd/tourette/facts.html>

NCCD. (2022). *Classroom adjustments: Tourette syndrome*. Retrieved from NCCD: <https://www.nccd.edu.au/professional-learning/classroom-adjustments-tourette-syndrome>

NHS. (2016). *Tourette syndrome and managing tics in the classroom*. Retrieved from Great Ormond Street Hospital for Children NHS Foundation Trust: https://media.gosh.nhs.uk/documents/Tourette_and_managing_tics_F0798_A4_bw_FINAL_Oct16_1.pdf

NHS. (2021, January 04). *Tourette's syndrome*. Retrieved from NHS: <https://www.nhs.uk/conditions/tourettes-syndrome/>

Tourettes Action. (2023). *About TS*. Retrieved from Tourettes Action: <https://www.tourettes-action.org.uk/7-about-ts.html>

Resources and Signposting

Useful websites:

<https://www.tourettes-action.org.uk/>

This site provides really helpful information for CYP, parents and professionals. It also offers a training module for education staff (see below). There are a range of helpful factsheets which can be downloaded for free.

For example:

- Key facts for teachers
- Functional tic disorder (and how this differs from Tourette's)
- TS and exam revision tips
- Behavioural problems and Tourette's

These can be accessed here: <https://www.tourettes-action.org.uk/rescat-2-children--young-people.html> and <https://www.tourettes-action.org.uk/64-resources.html>

Tourette's Action have also developed the TS Passport. This is a four-sided document where young people with TS can add information about their tics and

social situations that heighten/lessen their tics and a space for any medication, accompanied with their photograph. This is a perfect document for teachers, especially supply teachers as they can quickly and easily understand about the child's TS. It can be downloaded here: <https://www.tourettes-action.org.uk/105-ta-passport.html>

The following article looks at supporting young people with Tourette Syndrome in Secondary School, you are able to request to view this for free.

https://www.researchgate.net/publication/265646007_Supporting_students_with_Tourette_syndrome_in_secondary_school_A_survey_of_staff_views

Great Ormond Street Hospital also provide information on how to support young people within a classroom:

https://media.gosh.nhs.uk/documents/Tourette_and_managing_tics_F0798_A4_bw_FINAL_Oct16_1.pdf

Other helpful websites are:

<https://tourette.org/about-tourette/overview/what-is-tourette/>

<https://tourette.org/resource/tics-classroom-educators-guide/>

https://media.gosh.nhs.uk/documents/Tourette_and_managing_tics_F0798_A4_bw_FINAL_Oct16_1.pdf

Videos:

<https://www.youtube.com/watch?v=eJRGDITFCv0&t=26s> (for CYP)

<https://www.youtube.com/watch?v=M8clZP-PI2Y&t=21s> (for all)

Staff Training:

Tourette's action provides online training for education staff: In this module, you will learn what Tourette Syndrome is, co-occurring features and differences that accompany it, how it affects an individual and what can be done to help and understand. Unfortunately, a lot of what we know about Tourette's is what we have seen in the media but in fact, in reality, TS presents very differently.

<https://www.tourettes-action.org.uk/learningplatform/#/>

Recommended books:

- Understanding Tourette Syndrome: A guide to symptoms, management and treatment by Carlotta Zanaboni Dina
- Tic Disorders: A Guide for Parents and Professionals by Chowdhury and Murphy.
- It's NOT All About Swearing!: A Practical Guide to Tourette's Syndrome for Parents in a Post-Pandemic World by Mandy Barnett

Books for CYP

- Can I tell you about Tourette Syndrome?: A guide for friends, family and professionals by Mal Leicester
- Me and my Tourette's by Siâna Stodd
- Self-Control: Activity book for teens with Tourette's Syndrome, Calm your mind and find your best self with mindfulness pages: To Manage Anxiety understand your emotions and develop your communication skills