

Tourette's Syndrome

Tourette's Syndrome is a neurological disorder characterised by motor (body) or vocal tics. There is, at present, no definitive cause for TS, although in at least half of all cases there is a familial link. TS generally starts in primary school but really becomes apparent between the ages of 10 and 14. The tics are involuntary and their severity will come and go from one day to the next. Many people with TS do have some control over their tics, but the tics may well reappear with renewed vigour once the control is relinquished. Things often improve as the young person reaches adolescence. The tics can be very distressing for the young person, causing embarrassment and possible teasing from friends and even family. It is four times more common in boys than in girls.

All children with Tourette's Syndrome will have tics of some sort. Tics are rapid, involuntary movements or sounds that are repeated over and over. They are very difficult to control, and the process of trying to keep them to a minimum can be the cause of constant stress and anxiety. Try to keep this uppermost in your mind when dealing with TS!

Over the past year, this disorder has gained much wider recognition following a couple of excellent television programmes, and several well-known people have described how TS has affected them in their school, social and working lives.

The most common motor tics may include:

- eye blinking or rolling
- squinting
- nose-twitching
- lip smacking
- tongue-thrusting
- shoulder shrugging
- arm extending ... and others.

The most common vocal tics may include:

- throat-clearing
- grunting
- spitting
- swearing
- stammering
- hissing
- shouting, barking, moaning ... and others.

Associated Symptoms

As many as three-quarters of children will also have attention difficulties (ADHD) and many will be dyslexic and/or dyspraxic; at least half may suffer from obsessive compulsive disorder (OCD) and suffer anxieties including phobias. It is also associated with Autistic spectrum disorders, eating disorders and sensory sensitivity.

Other symptoms can include moodiness, compulsions, obsessions and impulses, echolalia (repeating of others' words), echopraxia (mimicking others' actions), palallia (repeating internal words or thoughts), coprolalia / copropraxia (swearing / gesturing obscenities), stuttering, apraxia (non-neurological inability to carry out an action, such as reading) and self-destructive behaviours (eg: head banging, eye poking and lip biting).

Problems

The young person with TS may be quick to lose his temper, may over-react in certain situations, will have difficulties with impulsivity, and may display defiant behaviour to those in authority. At school they may have problems organising their work, playing / working quietly, speaking at the appropriate time (they may interrupt others, or encroach on their space, work area etc). They may appear not to listen to the teacher; they may lose vital papers, books, other items necessary for school or home activities. They may take part in physically hazardous activities without having thought through likely outcomes.

Treatment

TS cannot be cured but often treatment can achieve some level of control of symptoms, to allow the individual to function as normally as possible. Certain drugs such as clonidine or haliperidol can subdue TS and its associated tics. Your doctor will advise you. Any medication given needs to be closely monitored so that it can be adjusted according to the progress of the disorder. Drugs often have some side effects in some patients e.g. depression.

Helpful hints for home and school:

- Do not draw attention to the tics: try to ignore them and take action to ensure peers do so to
- allow 'time-out' periods for him to express his tics privately in a safe place. This will help avoid an outburst in the classroom / at home
- in class, allow the pupil to sit near the door for an easy, non-disruptive exit when necessary
- ensure the pupil is not being teased or bullied by his peers / siblings / other relatives
- focus on the behaviour you want to reinforce: the more attention paid to the positive behaviour, the more likely he is to repeat it
- find a reward that is satisfying - concentrate on rewarding only one or two behaviours at a time. The reward system chosen must be closely monitored and reviewed (over-use of rewards will lead to diminishing returns)
- where tics interfere with speech, have systems to allow the pupil to record responses in private
- Arm and head tics may make written work difficult. The use of a scribe, word processor, speech to text software and extra time in class and in exams may be useful
- ensure his medication is regularly monitored
- avoid confrontational situations: aim to divert attention
- be consistent when issuing sanctions. Negotiate these sanctions with the pupil beforehand in order that he understands the consequences of any aggressive or anti-social behaviours
- be consistent with approaches in all aspects of the pupil's life. Do not allow the pupil to receive mixed messages from different people
- all agencies (parents, teaching staff, psychologists, etc) must work closely together.

Other Useful Contacts

Tourettes Action, Southbank House, Black Prince Road, London SE1 7SJ

Website: www.tourettes-action.org.uk

Helpline: 0845 458 1252 (to speak to an advisor)

Email: help@tourettes-action.org.uk

Admin: 020 7793 2356

This organisation has helpful leaflets, a reading list, a frequently asked questions section on their website covering many areas, and hold regular family networking events for members.

Note: The OAASIS Information Sheets use 'he'/'his'/'him' rather than the cumbersome 'he / she'/'his / her'/'him / her'. No sexism is intended.

Reading

See also OAASIS information sheet '**Books – where to find them**'

OAASIS publishes A First Guide to Tourette's Syndrome in its First Guide series £4.00 plus p&p. You can ring or write to OAASIS at the address over the page for a publications list / order form or visit the website at www.oaasis.co.uk

Routledge Education (member of the Taylor Francis Group)

Web: www.routledgeeducation.com (academic and research based) or www.routledgegeteachers.com for teachers.

Tel: 020 7017 6563 (Marketing)

Jessica Kingsley Publishers

Website: www.jkp.com

Email: post@jkp.com

Tel: 020 7833 2307

Sage Publications: For all professionals working in schools and educational settings (includes Paul Chapman Publishing and Lucky Duck books).

Web: www.sagepub.co.uk

Email: market@sagepub.co.uk

Try also the internet book shop www.amazon.co.uk

Internet Sites

www.tsa-usa.org is the website of The TSA Inc based in the USA

www.tourettes-disorder.com is another American website with detailed info including diagnostic criteria

www.mentalhealth.com/book/p40-gtor.html has The Mental Health pages on TS



www.cambianeducation.com

Cambian is the largest provider of specialist residential education and care for young people with Autism, Asperger Syndrome and other associated complex needs in the United Kingdom. Cambian is trusted by hundreds of parents and over 70 Local Education Authorities

OAASIS publications

- SEN Information Sheets
- First Guide to ...
- Cards explaining 9 learning disabilities
- Legal advice Information Sheets
- SEN 'How to' guides

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