

Tourette Syndrome

Tourette Syndrome is a neurological condition characterised by motor (movement) or vocal tics. There is, at present, no definitive cause for TS, although in many cases there is thought to be 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 in a waxing and waning way. Many people with TS do try to control some of their tics but the tics may well reappear with renewed vigour once the control is relinquished. Things often improve as the young person reaches late adolescence. The tics can be very distressing for the young person, causing embarrassment and possible teasing from friends and even family. It is three to four times more common in boys than in girls.

All children with Tourette Syndrome will have tics of some sort. Tics are rapid, involuntary movements or sounds. 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 years, 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. Despite being sensationalised by the media, only 10% of people with TS actually swear uncontrollably (known as coprolalia). The remaining 90% do not swear. TS does not affect intelligence or IQ.

The most common tics are listed below but there may be others

Motor tics

- eye blinking or rolling
- squinting
- nose-twitching
- lip smacking
- tongue-thrusting
- shoulder shrugging

Vocal tics

- throat-clearing
- grunting
- stammering
- hissing
- shouting
- barking

Associated Symptoms

As many as three-quarters of children with TS will also have attention/hyperactivity difficulties (ADHD) and/or obsessive compulsive disorder (OCD).

Other symptoms can include moodiness, compulsions, obsessions and impulsions, echolalia (repeating of others' words), echopraxia (mimicking others' actions), palallia (repeating internal words or thoughts), coprolalia/copropaxia (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. At school he may have problems organising his work and significant social difficulties due to bullying by peers and classmates.

Treatment

TS cannot be cured but often treatment can achieve some level of control of symptoms.

Certain drugs

such as Clonidine or Haliperidol can subdue TS and its associated tics but these drugs often have significant side effects. The advice of a doctor must be sought. Any medication needs to be closely monitored so that it can be adjusted according to the progress of the disorder.

Helpful hints for home and school

- all agencies (parents, teaching staff, psychologists, etc) must work closely together
- The national charity Tourettes Action can provide support and guidance.
- ensure medication is regularly monitored
- do not draw attention to the tics: try to ignore them and take action to ensure peers do so too
- allow time-out periods so tics can be expressed privately in a safe place. This will help avoid more public outbursts

- in class, allow the pupil to sit at the front to enhance concentration
- ensure no teasing or bullying is taking place
- where tics interfere with speech, have systems in place to allow responses to be recorded 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
- avoid confrontational situations: aim to prevent situations escalating out of control
- be consistent when issuing sanctions.

Negotiate

these sanctions beforehand in order that the consequences of any aggressive or anti-social behaviours are understood

- be consistent with approaches in all aspects of life.
- Be sure to avoid mixed messages from different people.

Obsessive Compulsive Disorder

USEFUL CONTACTS

Tourettes Action

A UK wide charity offering information, help to get a diagnosis, grants, publications, short films, ID cards, two conferences per year, teenage adventure camps, local support groups.

A very useful leaflet called 'What makes us Tic?' a general introduction for those recently diagnosed with Tourette Syndrome, their families and colleagues, and for those who wish to know more about the condition.

Website: www.tourettes-action.org.uk

Helpline: 0300 777 8427

Email: help@tourettes-action.org.uk

Contact a Family

UK wide advice on all aspects of caring for a child with any special need, disability or rare disorder; national SEN help line; downloadable fact sheets and publications; Connected magazine; local support groups and parent reps; campaigns and research etc.

Website: www.cafamily.org.uk

Tel: 0808 808 3555

Email: info@cafamily.org.uk

They also run a separate site Making Contact where you can share your experiences, get advice or local support from other parents with children with the same condition.

www.makingcontact.org.uk

READING

See the Cambian information sheet 'Books – where to find them' for a list of specialist publishers with a huge range of books.

USEFUL INTERNET SITES

The Henry Spink Foundation

a UK charity for research and information for parents of children with severe disabilities.

www.henryspink.org/tourette_syndrome.htm

National Tourette Syndrome Association

a USA organisation, the website has lots of relevant information.

www.tsa-usa.org

Tourette Syndrome "Plus" is the website of Leslie E. Packer, PhD (American) a NYS-licensed psychologist who specialises in Tourette's Syndrome and the associated conditions:

www.tourettesyndrome.net

Acknowledgement: We would like to thank Tourettes Action for their help in giving advice for and checking the content of this information sheet.

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CAM613 Date of preparation 22/10/18