

Special Education Support Service: Information on Tourette Syndrome

Introductory Note: *The Special Education Support Service wishes to acknowledge and thank Breeda Quigley, Learning Support Teacher, Co. Mayo, for her input in the compilation of this document. Breeda has completed postgraduate research on Tourette Syndrome.*

Note: The following is the stated position of the DES with regard to the educational provision to be provided for a child who has special educational needs arising from a specific assessed syndrome. See Circular 08/02 for further information.

“The level of additional support to be provided for children who present with a particular syndrome e.g. Down Syndrome, William's Syndrome and Tourette's Syndrome will be determined following consideration of psychological or other specialist reports which details the nature and degree of the child's special educational needs”.

Definition and Characteristics:

Tourette Syndrome (TS) is a neurological disorder. It is considered to be a life-long condition that is biochemically based and genetically transmitted. Literature widely supports autosomal dominant inheritance, which means that if an individual has the disorder, there is a 50-50 chance that each offspring will inherit the gene. A neurochemical basis for TS suggests that there is an imbalance in the function of the neurotransmitter Dopamine. Estimates of prevalence can vary according to the definition employed and the design of the study.

There is no cure for TS, although in many cases tics become less evident as the individual gets older. Medication such as haloperidol (Haldol), pimozide (Orap), fluphenazine (Prolixin), and clonidine (Catapres) may also help to control symptoms, which although involuntary, can be suppressed for periods of time, usually followed by an outburst of tics known as a tic storm.

Clinical assessment of the condition involves taking a complete family and personal history along with observing the characteristic symptoms. For a diagnosis to be made, it is essential that multiple motor tics (twitches) and one or more vocal tics (noises) are present for at least one year. These tics may appear simultaneously or at different times, and tend to wax and wane. The onset of symptoms is usually before the age of 21, the average age of onset being seven. The anatomical location, number, frequency, complexity and severity of symptoms will change over time.

Both motor and vocal tics are considered to be either simple or complex. Simple motor tics include tics of the head and face such as excessive eye-blinking and squinting, eye-rolling, nose twitches, mouth twitches, making faces, tongue protrusion, nodding or tilting of the head sideways, shoulder shrugging, arm jerking and extending, leg kicking and knee jerks, and abdominal contractions such as pulling in the tummy.

Complex motor tics include the smelling and licking of objects, spitting, touching parts of one's own body and touching others, unusual gait such as twirling, squatting, hopping, skipping, and bending down.

Simple vocal tics include sounds such as repetitive sniffing, snorting, throat clearing, coughing, and gulping, while more complex vocal tics include grunting, barking, yelping, quacking, whistling and belching.

Other characteristic features of the syndrome include:

- echolalia (repeating or imitating what other people say);
- echopraxia (copying or imitating what other people do);
- palilalia (repeating oneself over and over, or constantly repeating the last word or phrase uttered by oneself);
- palipraxia (which involves repetitive movements such as knotting a tie over and over again), and
- copropraxia (which is involuntary but inappropriate cursing and swearing).

Although its range of expression may be complex and varied, there is only one condition known as Tourette Syndrome. While many individuals have "pure" TS without associated disorders, others have to deal with co-existing problems such as Obsessive Compulsive Behaviour (OCB), Attention Deficit Hyperactivity Disorder (ADHD), depression and/or anxiety and other psychopathology.

Implications for Learning

Most people with Tourette Syndrome have been assessed as having normal intelligence. Therefore, if a child with the syndrome is having problems with schoolwork, there are a number of possible reasons that might be explored. There may be primary problems implicit in the disorder itself such as some form of learning disability. Problems may also stem from coping with tics, attention deficits and hyperactivity, obsessive-compulsive behaviours, social and emotional problems, low self-esteem, or side effects of medication.

It has been claimed that such pupils have particular difficulty with coding, visual-motor co-ordination, verbal receptive skills and verbal fluency, mathematics, handwriting and completing homework. Weaknesses in reading skills including oral reading skills and reading comprehension, writing skills and mechanics such as spelling and punctuation, have been reported more frequently in relation to children with Tourette Syndrome. The latter has been critically questioned by some researchers in the field who argue that frequency and type of learning difficulties in children with TS do not differ significantly to the general population as a whole.

Implications for Teaching

The following all have implications for the teacher, the student and his / her classmates:

- Tics such as severe head shaking, neck stretching or eye rolling may render the child unable to look straight at the teacher for a continuous length of time, or render them unable to read easily.
- Hand tics could possibly interfere with writing, making it illegible at times.
- Loud and complex vocalisations may interrupt the flow of speech or disturb the other children in a class.
- Visuo-spatial deficits might result in the child having difficulty with copying things from the blackboard and from books when doing homework.
- Problems with attention and impulsivity can cause disruptions in classroom routines.
- Tics can impede on tasks with strict timing criteria, resulting in much lowered scores that can lead to inaccurate conclusions of decreased ability or aptitude.
- Repetitive eye blinking or head jerks could potentially interfere with visual scanning and perceptual integration.
- Complex tics might interfere with the sustained motor output required for written tasks such as completing paper-and-pencil arithmetic problems or handwriting.
- The mental and physical energy exerted to suppress tics may hinder sustained attention and, consequently, other cognitive functions such as auditory processing and short-term memory.
- Children with obsessions may become pedantic in their talk, and often have a need for a strict routine and for perfection.
- Homework may take hours in excess of normal and may never get completed.
- Children with TS may often appear not to be listening when spoken to, may have difficulty organising things, may be easily distracted and tend to fidget.
- They may answer questions directed at other children in the class. In more extreme cases they may show inappropriate and severe aggression.
- Side effects of medication may cause blurring of vision, school refusal and sometimes depression.
- Children with TS may be often teased and bullied because of their tics and noises.

Teachers may therefore need to modify teaching styles accordingly. The Tourette Syndrome Association of Ireland (and indeed their sister associations in the US and UK) may be contacted for further help (*see next page*). There are an increasing number of books available on Tourette Syndrome, although most of this literature is published in the US and Britain.

Extra Resources / References

Books

1. Bronheim, S. (1994) *An educator's guide to Tourette syndrome*
New York: Tourette Syndrome Association, Inc. Download from <http://tsa-usa.org/> Cost: \$3.00
2. Bruun, R.D., & Bruun, B. (1994) *A mind of its own-Tourette's syndrome: a story and a guide*
Oxford: Oxford University Press. ISBN: 0195065875 Cost: \$35.00
3. Carroll, A. & Robertson, M. (2000) *Tourette syndrome: a practical guide for teachers, parents and carers* London: David Fulton ISBN: 1853466565 Cost: £18.50
4. Comings, D. E. (1992) *Tourette syndrome and human behavior*
California: Hope Press. ISBN: 1878267272 Cost: \$22.50
5. Robertson, M., & Baron-Cohen, S. (1998) *Tourette syndrome: the facts*
Oxford: Oxford University Press. ISBN: 019852398X Cost: £10.00 (see www.tsa.org.uk)
6. Shapiro, AK., Shapiro, E., Young, J., & Feinberg, T. (1988) *Gilles de la Tourette syndrome (2nd. ed.)*
New York: Raven Press. ISBN: 0881673404 Cost: ??
7. Shimberg, E. (1995). *Living with Tourette syndrome.*
New York: Simon and Schuster. ISBN: 068481160X Cost: \$13.00

Support Organisations

1. **Tourette Syndrome Association of Ireland**, Carmichael House, North Brunswick Street, Dublin 7.
(01) 872 5550
2. **Tourette Syndrome (UK) Association**, PO Box 26149, Dunfermline, KY12 7YU, Scotland.
(00 44) 845 458 1252 Website: <http://www.tsa.org.uk> E-mail: enquiries@tsa.org.uk
3. **Tourette Syndrome Association, Inc.** 42-40 Bell Boulevard, Bayside, NY 11361 USA
(718) 224 2999 Website: <http://tsa-usa.org> E-mail: ts@tsa-usa.org