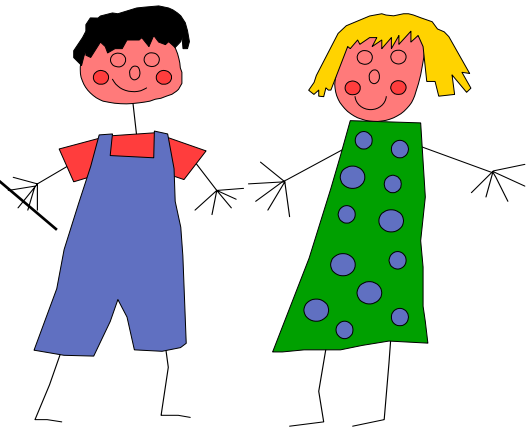




An OAASIS Publication
for Parents and Professionals

**TOURETTE'S
SYNDROME**



Tourette's Syndrome

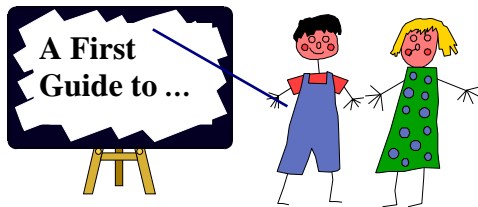
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OAASIS

*Office for Advice, Assistance,
Support and Information on Special Needs*

*OAASIS is a part of **Cambian Education Services***





Tourette's Syndrome

A First Guide to Tourette's Syndrome Price: £4.00

by Pauline Davies, 1998

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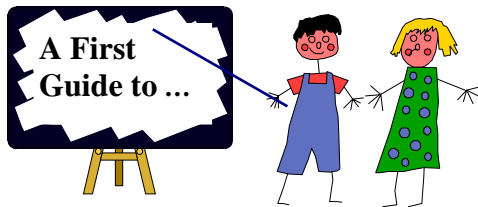
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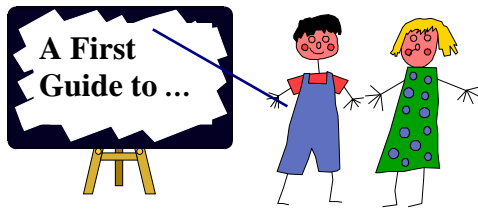
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Tourette's Syndrome About First Guides

- **This First Guide** was developed at Grateley House School as part of a range of guides being prepared for and distributed by OAASIS (Office for Advice, Assistance, Support and Information on Special Needs). They are designed to provide a quick and easy reference pack of information on various learning difficulties.
 - **OAASIS** offers:
 - a **telephone Helpline** for advice on matters to do with special education. Ring **01590 622880** usually manned between 10 and 4.30p.m., Monday – Friday.
 - various **publications** including
 - Free Information Sheets on various learning difficulties and other aspects of special education.
 - The *First Guide to ...* series. Other titles are listed on the opposite page.
 - *What is?* cards. Small cards describing briefly a disability. Useful for informing others. Cards are available on: ADHD, Asperger Syndrome, Attachment Disorder, Autism, Dyspraxia, Epilepsy, Obsessive Compulsive Disorder, Semantic Pragmatic Disorder and Tourette's Syndrome.
 - *Do You Know Someone with Autism?* booklet. Written by a former teacher at The Forum School for the brothers, sisters and classmates of a child with autism.
 - **OAASIS** can be contacted by writing to OAASIS at Brock House, Grigg Lane, Brockenhurst, Hampshire SO42 7RE; sending a fax to 01590 622687; emailing oaasis@cambianguroup.com or ringing the Helpline.
 - **Grateley House School** offers residential education (with a waking day curriculum) for young people aged 9-19 years with Asperger Syndrome or other associated syndromes requiring similar care, education and therapeutic interventions. The school is sited in a large country house near Andover, in Hampshire, within its own grounds of several acres.
 - Grateley House School and OAASIS are a part of Cambian Education Services. For further information on the Cambian Education schools and colleges please phone 0800 288 9779.
 - OAASIS welcomes contributions from families, professionals, and individuals who would like to contribute ideas for inclusion in the pack.
 - There may be a small charge for the Guides to cover OAASIS printing and packing costs. See the OAASIS Publications List for a full range of literature available.
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Tourette's Syndrome

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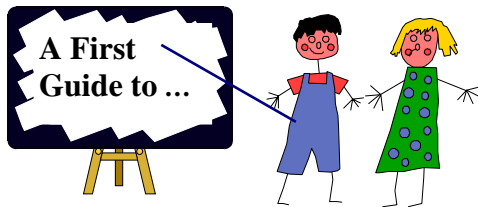
Difficulties Encountered by the Young Person with Tourette's Syndrome

Associated Disorders which may accompany Tourette's Syndrome

Helpful Hints for those working with Young People with Tourette's Syndrome

Acknowledgements and Recommended Reading

Other useful OAASIS publications



Tourette's Syndrome A Basic Introduction

Tourette's Syndrome is a hereditary, neurological disorder characterised by **motor** (body) or **vocal tics**. The tics are involuntary and will wax and wane from day to day and as the young person grows and matures.

It is three to five times more common in boys than girls.

Things often improve as the student reaches adolescence.

The tics are very distressing for the young person and can cause embarrassment and teasing from peers, and even from some members of the family.

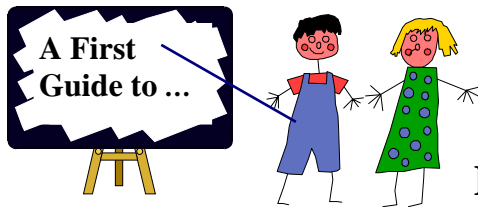
Tics are the commonality in all children with Tourette's Syndrome. The tics are difficult to control and the process of trying to control them can cause stress and anxiety. Tics are classified as simple or complex, according to how many parts of the body are affected.

The most common motor tics range from eye-blinking, shoulder-shrugging, and arm-extending.

The vocal tics may include throat-clearing, grunting, spitting and swearing.

The tics can be helped by certain drugs, such as clonidine and haloperidol.

Medication needs to be closely monitored in order that it can be adjusted to the progression of the disorder.



Tourette's Syndrome Difficulties for Young People with TS

The most common difficulty experienced by young people with Tourette's Syndrome is their inability to control their tics, which causes frustration and anxiety.

The tics may change in their nature and in their severity, and may disappear altogether for periods of time.

Any attempt by the young person to suppress the tics may simply defer a more severe episode of tics at some later stage - a sudden release after a short 'bottling up' period.

The tics may increase when the young person is tense or under stress, and can be eased when the student relaxes or concentrates on a motivating or rewarding task.

The following behaviours may be noted in conjunction with tics:

- quick temper
- over-reaction
- mood changes
- difficulties with impulse control
- oppositional and / or defiant behaviour
- aggression

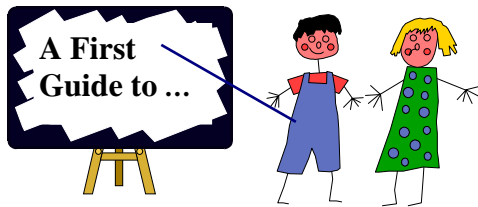
As well as specific behaviours, the young person with Tourette's Syndrome may well have difficulties which inhibit educational achievement.

Such difficulties include:

- appearing not to listen attentively
- may talk incessantly
- may have difficulty in organising work
- often interrupts or invades others' space
- often loses things and appears disorganised
- may enjoy dangerous pursuits without considering the consequences.

One of the major handicaps for the young person with Tourette's Syndrome is low self-esteem. Living with TS can be very debilitating, creating stress and anxiety in both the younger person and within the family.

It is vitally important for everyone working with the sufferer of Tourette's Syndrome to fully accept the individual and value the contribution he or she can make across the different facets of his or her life.



Tourette's Syndrome

Associated Disorders

Not all young people with Tourette's Syndrome have co-morbidities (associated disorders), but some will.

1. The main associated problem is ADHD (Attention Deficit / Hyperactivity Disorder). This is present in about 60% of cases.

ADHD sufferers have difficulty with

- concentration
- impulsivity
- hyperactivity

They can be **demanding** and **difficult to please**. They are **easily frustrated**. They may be **oppositional** and **defiant** and will be **easily led** by others.

These difficulties lead to particular problems for the student in the classroom. They student will

- be easily distracted
- have problems remaining on task
- often fidget (hardly ever still)
- find turn-taking difficult
- be unable to concentrate well enough to listen to instructions
- rarely complete a piece of work
- interpret information poorly
- be unable to sustain his or her efforts
- be unable to resist impulses, ie. interrupting.

When the Attention Deficit is affecting academic progress, medication, such as ritalin, may be given to reduce the symptoms.

2. Obsessive / Compulsive Disorder. This is another distressing co-morbidity that may accompany Tourette's Syndrome.

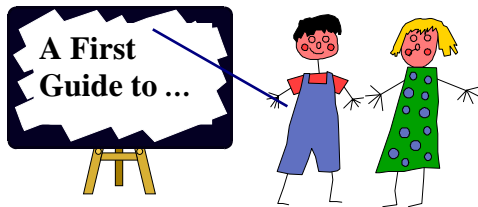
The obsessions are stereotyped, irresistible thoughts, ideas and images which intrude into the pupil's mentality.

They may be short-lived or last for a considerable period.

Such obsessions may severely hamper a pupil's progress.

The compulsions are actions that generally arise from the pupil's obsessive thoughts, ie if a pupil is obsessed with achieving perfection in a piece of work, the compulsive behaviour would be the writing and re-writing of the work until it is perfection in the eyes of the student.

Such obsessions / compulsive behaviours can be very frustrating, especially for the teacher and parent.



Tourette's Syndrome

Helpful Hints

1. Managing Behaviour

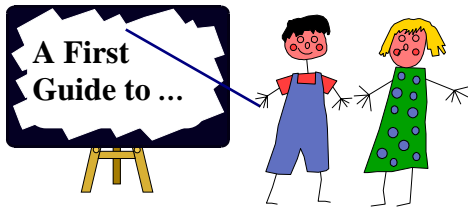
- Do not draw attention to the tics: ignore them
- Allow the pupil to have 'time-out' periods to express his or her tics privately in a safe place. This will help avoid an outburst in the classroom.
- Allow the pupil to sit near the door for an easy, non-disruptive exit when necessary.
- Ensure the pupil is not being teased or bullied by his or her peers.
- Focus on the behaviour you **want** to reinforce: the more attention paid to the positive behaviour, the more likely the pupil is to repeat it.
- Find a **reward** that is satisfying to the pupil - 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).
- The pupil needs to be closely monitored by the child psychiatrist, especially if medication is prescribed.
- Avoid confrontational situations: aim to divert the pupil's attention.
- Be consistent when issuing sanctions. Negotiate these sanctions with the pupil beforehand in order that he or she 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 must work closely together.

2. Improving Learning

The main factors affecting learning are likely to be those associated with ADHD. Where this is severe, medication such as ritalin may be useful.

Consideration of the following points may help the pupil make steady academic progress and so reach his or her full potential.

- Draw up an **Individual Plan** to address the specific learning difficulties.
- Create **distraction-free** areas within the classroom to promote concentration and to assist the pupil in keeping on task.
- Set short, **achievable tasks** and provide **immediate feedback**.
- Allow **extra time** for certain assignments to alleviate stress and anxiety, as this can cause an increase in tics.
- Develop the **pupil's strengths** and find an activity / interest which can be a channel for their energy and motivation. This is important for **developing self-esteem**.
- Let the pupil feel he or she **is valued** and **give praise** whenever the opportunity arises.
- Provide **visual cues** wherever possible.



Tourette's Syndrome

Helpful Hints

- Ensure that instructions are given **clearly and concisely**. Avoid inferred meaning. Ask for **feedback** at each stage from the pupil to ensure he or she has understood.
- **Boundaries** must be clearly set and explained - insist that these are adhered to.
- **Be prepared for set-backs**, as the symptoms will wax and wane.

3. Learning Difficulties

More than half of young people suffering with Tourette's Syndrome have associated learning difficulties, generally specific, which results in a discrepancy between the pupil's ability to learn and his or her achievement.

Very often the learning difficulty has arisen due to ADHD factors. Hence, it is important to improve the pupil's ability to concentrate and focus if the learning disability is to be rectified.

Included in the learning difficulties are specific types of reading, writing and numeracy and associated language problems.

Young people with Tourette's Syndrome may well have difficulty processing language. If they also have ADHD they may not listen clearly to instructions and will become confused and frustrated.

The tics will be the greatest inhibitor to the pupil. He or she may need time-out of the classroom to be able to express the tics in a quiet, private place.

A build-up of the tics will lead to an increase in tension and will sap the pupil's energy instead of this energy being diverted to maximising learning potential.

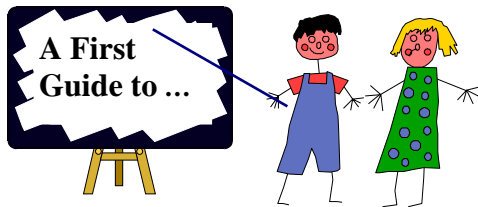
4. Aggressive, Explosive, and other Unusual Behaviours

Many Tourette's sufferers have a 'short-fuse' Temper outbursts may be frequent and they can quickly escalate to include aggression which results in physical assaults or damage to property.

Usually there is remorse immediately following such outbursts, but the effect on others - teachers, carers or parents - can be devastating.

Medication such as tegritol may well be tried where such behaviours are severe. Behaviour therapy may also be useful.

Some Tourette's sufferers may also display self-injurious behaviours. They may even enjoy the pain sensation that results. It is difficult to know whether this behaviour is as a result of a complex tic or a compulsion.



Tourette's Syndrome

Acknowledgements and Recommended Reading

The following books and leaflets were consulted while compiling this First Guide, and would be recommended reading for any parent or professional dealing the Tourette's Syndrome:

Books

Children with Tourette Syndrome: A Parents' Guide

Editor: Haerle, T; 1992. Woodbine House.

Tourette Syndrome - a practical guide for teachers, parents and carers

Amber Carroll & Mary Robertson. 2000. ISBN 1-85346-656-5

Available from David Fulton Publishers. Website www.fultonbooks.co.uk Email orders@fultonbooks.co.uk Tel: 0207 405 5606.

Tourette Syndrome and Human Behaviour

Author: Comings, D; 1990. Hope Press.

Leaflets

An Educator's Guide to Tourette Syndrome

Author: Bronheim, S; 1994. Tourette Syndrome Association Inc (USA)

Gilles de la Tourette's Syndrome: A Guide for Parents

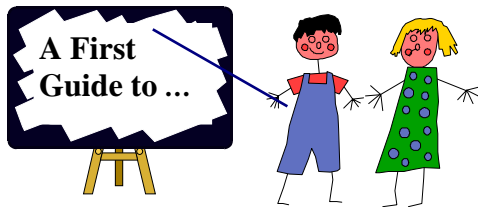
Authors: Robertson M; Eapen V; 1994. Tourette Syndrome (UK) Association.

A Guide to the Management of Gilles de la Tourette's Syndrome

Authors: Robertson M; Eapen V; 1994. Tourette Syndrome (UK) Association

Coping with Tourette's Syndrome in the Classroom

Information leaflet from the Tourette Syndrome (UK) Association.



Tourette's Syndrome Support Groups and Websites

Support Groups:

The Tourette Syndrome (UK) Association

PO Box 26149, Dunfermline, West Fife, KY12 7YU.

Helpline: 08454 581252

Website: www.tsa.org.uk

This organisation provides useful information to download from their website. They can be contacted by parents or professionals or people with Tourette's Syndrome.

Websites:

As well as the TSA one given above -

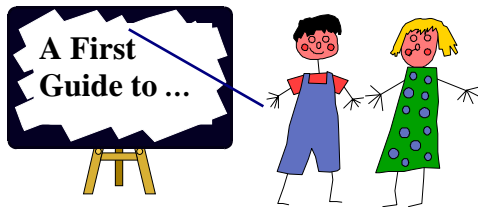
<http://www.bbc.co.uk/health/conditions/tourette1.shtml>

Three American ones:

www.mentalhealth.com/book/p40-gtor.html

<http://www.nlm.nih.gov/medlineplus/tourettesyndrome.html>

<http://www.tourettesyndrome.net/>



Tourette's Syndrome And check out ...

... the OAASIS Information Sheets –

- Tourette's Syndrome
- Exams and Access Arrangements for Students with Special Needs
- Finding a Special Needs School
- Independent Special Schools – what to look for
- Books – where to find them
- Forthcoming Conferences and Seminars from other organisations
- Useful Contacts and Websites

Visit the OAASIS website for the full list of free downloadable information sheets and other publications: www.oaasis.co.uk.