



Education Issues and Tourette Syndrome

an introduction for parents & schools

Edited by Claire Ball and Hillary Box

August 2008

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Tourette Syndrome (TS) affects one in a hundred children in mainstream schools and a much higher proportion in special schools.

This publication is written for both teachers and parents so that they can help children with TS to achieve their full potential within the education system.

This leaflet is a basic introduction as our experience suggests that many people are unfamiliar with TS, including educational professionals.

For more detailed information, please contact the Tourettes Action free Helpdesk on 0845 458 1252, or by emailing help@tourettes-action.org.uk.

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About Tourette Syndrome

Tourette Syndrome (TS), also known as multiple tic disorder and tic spectrum disorder, is named after Dr George Gilles de la Tourette, the French neurologist who first reported TS in medical literature in 1885.

TS is a neurological condition of unknown origin characterised by tics (involuntary movements and sounds). In a very significant number of children, these tics are only the tip of the iceberg. Nearly 90 per cent of children (and adults) with TS also have other behaviours, notably Obsessive Compulsive Disorder or Attention Deficit Hyperactivity Disorder.

One child in a hundred is thought to have TS. In SEN populations, the proportion is much higher – 25 per cent has been suggested. TS is also higher in children diagnosed with autistic spectrum disorders. One study found that eight per cent of children with autistic spectrum disorders also had TS.

Boys are three times as likely as girls to be diagnosed with TS.

Coprolalia (involuntary bad language), the most renowned but most misunderstood feature, affects only one person in ten.

Some children with TS have symptoms that are only mildly troubling. For others, symptoms are intensely disabling. Children with TS find themselves excluded from education, social activities and relationships. Children may also exclude themselves out of shame for their involuntary actions.

Symptoms

The symptoms of TS are motor and vocal tics (repeated movements and sounds). Tics are chronic and involuntary. They generally (but not always) start in childhood, often between five and seven years old. Motor tics start a little earlier than the vocal tics.

Both motor and vocal tics must be present for over a year for a diagnosis of TS to be made.

The range of tics is very broad, as illustrated in Table 1.

Table 1	Simple: <i>examples</i>	Complex: <i>examples</i>
Move-ment	Eye blinking, head jerking, shoulder shrugging and facial grimacing	Jumping, touching other people or things, smelling, twirling, and sometimes hitting or biting oneself
Sound	Throat clearing, yelping and other noises, sniffing, coughing and tongue clicking	Uttering words or phrases out of context, coprolalia (saying socially unacceptable words), and echolalia (repeating a sound, word, or phrase just heard).

Although tics are involuntary, most children and adults with TS can suppress them for a short time. Often there is a premonitory feeling or urge which is relieved by ticcing - this has been compared to the experience of sneezing, or trying to suppress a sneeze.

Tics are situational. They are often worse in stressful or boring situations and commonly vary in different environments, for instance, at school or at home. They can improve when a child is absorbed in a task such as sport or music. Tics tend to wax and wane in severity over various time periods.

Only about 12 per cent of patients seen in clinics have a syndrome consisting only of tics. The great majority have additional co-morbidities; most commonly Obsessive Compulsive Disorder (OCD) and/or Attention Deficit Hyperactivity Disorder (ADHD). Children may suffer from 'rages' with little provocation, usually followed by remorse. These elements can be more of a practical problem than the tics and can be less visible.

Effects on learning ability

People with TS have the same range of IQ as the rest of the population, with some subtle disparities of verbal and non-verbal domains. There is a tendency towards lower verbal IQ (intelligence that depends on verbal reasoning using language) in relation to performance IQ (eg visuospatial ability, puzzle solving, mathematics).

TS is not a learning disability but some of the symptoms and co-morbidities can have a substantial impact on a child's ability to learn. For example:

- Writing can be made difficult by movement tics, or obsessions relating to how things should be written.
- Movement tics involving eyes can make reading tasks very difficult, while vocal tics can make reading aloud a source of anxiety and embarrassment.
- Concentrating on a lesson can be hard if a child is trying to suppress tics.
- Impulsive traits can manifest as calling out or speaking out of turn in class.

Treatment

There is currently no cure for TS.

Most people with TS are not significantly affected by their tics or behaviours and do not require medication. There are medications which can help control the tics when they cause problems.

A current principle of treatment is that drugs are symptom-orientated ie predominantly for tics, for ADHD and for OCD. There are standard medical treatments for ADHD and OCD (which can be more troublesome than tics) which are also used in people with TS. Treatments for ADHD (eg stimulants like Ritalin) might, theoretically, make tics worse and were traditionally not recommended in TS. However, some of the most successful trials of drug treatment in TS have not supported this view.

Individual children react to different drugs with dramatic and unexplained variation. Children with TS of differing degrees of severity can find that their tics are well controlled by drugs, or alternatively that drugs have little to offer them. Adverse effects are also rather variable between individuals.

Undesirable side effects of drugs used in the treatment of TS can include weight gain, tiredness and depression.

Other therapies may be helpful. Psychotherapy can assist the child with TS and their family to cope. Some behavioural therapies can teach the substitution of one tic for another that is more acceptable. Relaxation techniques can alleviate stress that would otherwise make tics worse.

Managing TS in school

"I think overall it was the attitude of the school that helped most. The school really cared and they genuinely worked in partnership with me. Everything I suggested and asked for was tried."

It is a misconception that children with TS are easy to spot. Children with TS may cope with a minefield of issues everyday at school - sometimes so successfully that no one is aware of the problems.

They may become expert at disguising tics; eye tics are concealed by looking around the room; vocal tics by coughing or laughing; jerking tics by moving or 'messaging about'.

However, such success comes at a cost. Controlling tics requires a huge amount of concentration and energy. The child may be labeled disruptive or inattentive.

TS pupils often find writing difficult; the fine motor control and concentration needed for neat penmanship are not always possible and this can often mask a higher ability.

A number of techniques in the classroom and beyond may help.

Engage the peer group

Children with TS are an easy target for bullies. If possible, and only with the child's consent, a whole-school awareness of TS can minimise potential for bullying. This also lessens pressure on the child to explain or disguise tics, which may be helpful in itself.

The playground is another area that can cause problems. This is a time when tics may be released and other children can often be unkind. 'Circle time' or PHSE provides a chance to allow both the child with TS and other pupils to discuss problems related to TS.

“My son Thomas, aged eight, was recently diagnosed with TS and over a very short space of time went from fairly mild tics to loud and frequent vocal tics along with twirling, jumping, cartwheels, neck jerks and leg thrusts.

The head teacher helped Thomas to talk to his class about his condition and encouraged them to ask him questions, which he answered. He wasn't keen to tell anyone but she helped me persuade him it was best that people knew. She also told him to choose two friends who now buddy him if he has to go out of the classroom to tic. She lets him use the ICT room for this! He says he runs around and grunts and squeaks a bit and then goes back to class.

The head teacher also pointed out to Thomas that his friends were still his friends even though he now knew what was wrong with him. She said: “You feel like you have a big sign pointing at your head saying you've got Tourette's, but you must remember you are the same boy you were a week ago before you knew what you had.” That simple sentence made him feel a lot better.”

It may be helpful if the child can identify an adult at school whom they can trust and build a relationship with. Maintain open channels of communication between the child, the school and the family so that any incidents of bullying can be dealt with quickly and efficiently.

“My son had a terrific school looking after him and it was all down to one rather fabulous Head of Lower School. He moved from a small village school to a big all-boys Grammar School. The stress made the tics more severe and bizarre, including the most dreadful noises. Not a good start for a Y7 boy! Mr A took two bullies (who had been mimicking his tics) to one side and explained the situation and then gave them the task of looking out for Adrian, ie reporting anyone else doing the same foolish thing. It worked. The boys felt they had a role to play and Adrian was never mimicked again.

Mr A also got an older lad to watch out for Adrian on the bus. So he travelled to school without fear and went to school without fear. Adrian was voted form captain in Y9 - a tribute to the school and him.”

Allow the pupil to release tics

Children with TS should be allowed to leave the classroom, assembly etc as necessary. A room for the child to go to release tics can also help reduce bullying, as this gives the child the opportunity to tic in private and then return to their classmates.

They can, for example, be given a small laminated card to be used as a pass out of class when situations become stressful. Sitting near an exit means they can leave with minimal disturbance

Seating

The seating within a classroom can reduce bullying; at the back near a door is one place that appears to work. This way, the child is not being watched by everyone, and can leave the classroom if necessary.

“My daughter had a quiet room she could access any time she needed it: to let out tics, just have five minutes peace etc. She was allowed to leave the classroom any time she wanted. She used to sit by the door and slip out quietly. She wasn't penalised for not completing homework or class work and had a lot of extra help with spelling, maths etc in the SEN department to catch up.”

Reducing stressful situations

Any situation that is very quiet, for example assembly, may cause extra stress. Reading aloud can also be a source of embarrassment when vocal tics are bad. Excusing a child from such activities can help reduce anxiety.

Moving to a new school can also be a very stressful time. Preliminary visits before starting can help a child cope with the transition.

“She didn't have to wait in the queue for dinner but had a pass which allowed her and one friend to go to the top of the queue and collect their meals.”

Self-esteem

The attention that tics can attract, along with the feeling of being different from your peers, can often result in low self-esteem for children with TS. Rewarding pupils with praise for good work, good behaviour or overcoming personal challenges can be an effective way to motivate children and give them a sense of achievement.

Writing

Work can be recorded in different ways; eg with a teaching assistant to scribe; by laptop; recording ideas on audio, as mind maps or pictorially; or paired work, where a partner can be the scribe. Providing copies of written lesson notes or homework tasks can also be helpful.

“In exams, Hannah had a room of her own, extra time, someone was allowed to read and write if needed (due to hand tics, rolling eye tics and OCD problems).”

Setting work

Children with TS often have difficulty with concentration. Smaller chunks of work are more likely to be completed than long tasks. Children who have obsessions about completing work neatly or correctly may benefit from a gentle warning when the class is coming to the end of a session.

Exams

During tests and exams, it is advisable to allow the pupil to work in a separate room so tics can be let out. Oral tests or allowing a child to use a computer to type answers can be useful for those with handwriting difficulties.

“When the GCSEs were a year away, I was phoned by Adrian’s SEN teacher. She asked why I hadn’t requested extra time for him. My reply was that he’d never needed it. She told me she’d invigilated his maths exam and saw how long it took him to get his arm down to write (due to a tic). What if that happened again? I didn’t know, so it was so kind of her to tell me. We requested extra time and it was awarded. It made us feel that the school were really thinking of everything.”

Informing all staff

It is vital that every member of staff in contact with the child, not just the form teacher and SENCO, understands what to expect and the strategies being used. Regular staff room updates are very important, especially if there is a turnover of staff.

“I was in assembly and one of the other teachers told me to stop flicking my shoe. When I looked at him, my eyes rolled up in a tic and he kept me in at break for being rude. I was too embarrassed to tell him it was a tic”.

Members of staff should know that any changes in behaviour (eg frequent ticcing then none) may be a sign that something is amiss. It could be that the child is going through a period where the tics are not troublesome or the child may be hiding their tics.

Communication between home and school

Sometimes a child with TS who is not disruptive at school does not appear to have special needs. However, at home in a safe and secure environment, problems are really expressed. Close communication between parents and school is vital.

In the home, children with TS have space to tic, with no judgement placed on their actions or vocalisations. If a child has suppressed all day at school, they can now release their tics. The outburst of tics is likely to be long, with rapid movements and many vocalisations, possibly culminating in a rage attack. A child who is placid at

school can devastate the family home, breaking furniture, self harming and hurting others.

Communication with parents or carers is crucial for balance and continuity between school and home. If something has been noticed at school such as no tics, new tics, or an incidence of bullying, parents or carers should be informed. This helps to minimise home problems.

Parents or carers should have a named person at school to call if the child is having difficulties at home.

Knowing that their school and home talk to each other on a regular basis may help the child to manage symptoms better across both settings.

Homework

Many parents of children with TS know that trying to get them to sit down and do homework after a day at school can be impossible. This is usually the time to release an explosion of tics and emotions that have been largely suppressed all day at school.

There is a legal obligation to set homework, but the work will often take a child with TS twice or three times as long as classmates to complete. A compromise is to set a time limit on homework and accept that homework may not be finished within that period.

Before setting homework for a child with TS, consider:

- Does this child need to complete this to continue with their learning?
- Is this homework an essential part of the course?
- Can the child complete this homework in class?

Challenging behaviours

Some symptoms of TS can be particularly challenging for teaching staff.

Coprolalia

This is the term used for involuntary obscene or unacceptable language. It can be difficult to distinguish between involuntary swearing caused by TS and voluntary swearing. Coprolalia may also involve personally offensive or racist remarks.

It is often helpful to see how the child reacts to the outburst. Do they show remorse or embarrassment? If the swearing is a tic, it is not appropriate to discipline a child, nor is it helpful to ask them to stop. It is important for a teacher to ensure that the class understands why the child with TS is not being punished for swearing and that it would not be acceptable for anyone else to swear.

Very loud tics can be disruptive in a classroom environment. If a child is experiencing this type of tic, they may prefer to go to a place outside of the classroom to release tics.

Rage attacks

These can be frightening and destructive violent outbursts, often without provocation, or disproportionate to the trigger. Once begun, a rage attack has to be left to run its course. Rage may be linked to tic suppression. If possible, a teacher can help by identifying and diffusing stressful situations, before they escalate into a rage attack.

It can also help to talk through the event with the child afterwards, helping them to recognise triggers and reactions and look at other ways in which they could have responded. Role play can help children to practice strategies for coping.

Sexualised behaviour

This usually involves touching the person's own or other people's genitals. It can be embarrassing and upsetting for the child and poses complex problems for a school. In some cases, it will be possible to coach a child to substitute the touching of one body part for touching another, less taboo part, preferably with the permission of the person they are touching.

Medications in school

Schools should have policies on the management and administration of pupils' medicines and have systems for supporting individual pupils with medical needs.

The publication 'Managing medicines in schools and early years settings' (DfES/ Department of Health, 2005) provides advice for schools and their employers to help in the development of such policies. It explains the roles and responsibilities of employers, parents and carers, governing bodies, head teachers, teachers and other staff and of local health services. It considers staffing issues including employment of staff, insurance and training. Other issues covered include drawing up a health-care plan for a pupil, confidentiality, record keeping, the storage, access and disposal of medicines, home to school transport, and on-site and off-site activities. The document also contains a set of forms which can be photocopied by users — there are downloadable versions of these forms available from www.teachernet.gov.uk.

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If teachers suspect undiagnosed TS

If a teacher suspects a child may have undiagnosed TS, they should consider that a child with TS may present different symptoms at school and at home. Parents may not be aware of the symptoms a child is displaying in school. On the other hand, some parents become so accustomed to a child's tics that they do not see them as potential symptoms of an undiagnosed disorder.

Tourettes Action will supply a free information pack to anyone wanting to know more about TS, including a list of UK consultants who are familiar with the condition.

Teachers with TS

By Steve Barker BA LTCL PGCE - Music Teacher with Tourette Syndrome

When I was writing the foreword to the last set of Education Guidelines for Tourettes Action, I mentioned what I was doing to some of my pupils.

"That's all very well, Mr Barker," said one pupil, "but when are we going to get some guidelines on how to deal with a teacher with TS?"

I am seldom lost for words but that occasion was one of them. I hope this contribution will be the first step in recognising that the person in the classroom with TS could be the teacher; and that those with the condition can make a positive contribution to the education profession and the lives of children, particularly those who are dealing with the same or similar medical conditions.

Only some children with TS grow out of their symptoms, so the first point to make is that children with TS can grow up to become adults with TS. This may seem an obvious thing to say but I have met adults who are thoroughly understanding of a child with the condition yet react in a much less understanding way towards my symptoms. Logically, such a position makes no sense. All of the symptoms displayed by a child with TS could equally be displayed by an adult with the condition. I have been told that as an adult I should have more self control, yet my symptoms are just as involuntary as those of a child. We then come back to the old chestnut that symptoms are "not the done thing," but just as we must challenge and reassess that notion when faced with a child with TS, we need to do the same faced with a TS adult.

The awareness measures one would instigate if the school had a pupil with TS can be just as useful in supporting a teacher with the condition. Good material for citizenship education can be provided by discussing the condition and the issues surrounding it with children and allowing them to ask questions within a safe and non-confrontational environment. Your colleague with TS will provide vital guidance here and may be willing to talk to and take questions from children directly. It may also be advantageous to have similar discussions as a staff. Such events could even be formalised into an INSET session on which Tourettes Action would be happy to advise.

Knowledge about TS is key to effectively supporting those with the condition. I would like to recommend some further reading. "Tourette Syndrome - The Facts," by Mary Robertson and Simon Baron-Cohen (OUP) is a readable 80 page summary of the key medical points. There are many good autobiographies written by people with the condition but perhaps the most salient is Brad Cohen's "Front of the Class," (Van der Wyk and Burnham). Brad is a teacher in the USA who has TS. His account will give an invaluable insight into some of the experiences a colleague may be going or have gone through both inside and outside the classroom. I would particularly recommend this to management and governors of the school as any decisions you make will need to come

from a position of knowledge. Such knowledge will be particularly important should you encounter a prospective job candidate with TS to ensure the application and interview process is fair. You may also wish to familiarise yourself with circular 3/97 which deals with the impact of the Disability Discrimination Act on schools.

Regrettably, teachers with TS still encounter those who believe they are unsuitable teachers. Parents have requested that their child be removed from my class because of my TS. These situations require a two pronged strategy. Awareness methods can be used to reassure parents that the teacher is fully qualified to teach their child. However, this must also be backed up by the implicit message that such a request will not be acceded to and that the teacher has the support of their colleagues and the wider school community.

A very small minority of people within the profession itself hold similar views. Some head teachers, governors and inspectors still question the fitness of a person with TS to teach. Such accusations tend to fall into two categories. The first holds that the symptoms of TS are too distracting to allow effective teaching and learning to take place. The second argues that the so-called anti-social nature of TS prevents the teacher from being a suitable role model for the children and to maintain class control and discipline.

I would argue that such criticisms are unfounded. All people have mannerisms to a greater or lesser extent, it is part of what makes us unique individuals. Attempting to purge teachers of these, let alone the involuntary symptoms of a neurological condition, seems to remove the human face of teaching and teachers. A child will find it difficult to relate to such a person, leading the teacher to become distant from or irrelevant to those they teach. It is this which results in the breakdown of respect. If a child sees someone to whom they can relate, who has issues and difficulties in their life just as they do, that teacher will seem much more real. Out of that comes true and lasting respect, born not out of social status but human empathy. The 'Fitness to Teach' guidelines clearly support this point.

"People with disabilities and long term health conditions can and do make an important contribution to the overall school curriculum, both as effective employees and in raising the aspirations of disabled pupils and educating non-disabled people about the reality of having a disability."

Fitness to Teach. Paragraph B2 . Department for Schools, Children and Families 2007.

Teachers with TS are restricted by living or working in a social environment which views difference and diversity as a threat, as opposed to something which can be embraced and learned from. Misconceptions, preconceptions and prejudice all help to create such an environment and they need all the support their colleagues can give to fight these.

FOR PARENTS

Mainstream v. special needs

By Sandra Hutchinson

Which school - special, mainstream or other?

The UK government has made a firm commitment to increasing and enhancing inclusion opportunities. In its white paper on SEN provision, 'Removing Barriers to Achievement: The Government's Strategy for SEN' (2004), it suggests that children with severe and complex needs will continue to require specialist provision, but expects the proportion of children educated in special schools to fall, as mainstream schools develop the skills and capacity to meet a wider range of needs. However, it acknowledges that not all pupils get a fair deal at school and thus seeks to encourage schools and education providers to recognise and overcome barriers to learning and to embrace and promote inclusion.

Why choose a special school?

Like their mainstream counterparts, English state special schools must apply the National Curriculum and its assessment procedures, and have broadly the same duties and responsibilities to children in their care, as mainstream schools. The perceived advantages are that class sizes tend to be much smaller, even exceeding one-to-one help in some cases; work is usually geared to the individual rather than to a group; children have a peer group with similar needs and therefore don't appear different; and staff generally have an excellent understanding of the needs of the children and how to address those needs.

A statement of educational need is invariably required to secure a place, often a lengthy and stressful process. (Once a special school is named in a statement, the school is under a duty to admit the child.)

Critics say special schools don't push the children as much academically, have lower expectations, and that mixing with other children with the same needs doesn't create a model or even a comprehensive peer group. However, special schools must be doing something right for, according to the 2005/6 Ofsted annual report, 21 per cent of special schools were judged outstanding (2 per cent inadequate). By comparison, the figures for mainstream secondary schools were 10 per cent outstanding and 13 per cent inadequate, and for mainstream primary schools 95 and 7 per cent respectively.

Inclusion

An increasing number of mainstream schools see themselves as inclusive, though not all have experience, skills and resources to make effective provision. The Disability Discrimination Act 2001 calls for schools to make reasonable adjustments to prevent pupils with disabilities being at a disadvantage and to plan to improve their access to the curriculum.

Denying a child a place in a mainstream school may be discriminatory, but not all mainstream schools have the capacity to cope. Some staff aren't confident about admitting and supporting pupils with more severe complex needs, especially those with social and behavioural difficulties. Overriding concerns about the behaviour of some children and the detrimental effect it has on other children in a class resonate loud and clear. Head teachers struggle to marry the rights of the individual child with those of the whole school class.

By attending a mainstream school it's suggested that children are on an even footing, not marked out as different. Yet children with special needs are often perceived as different and reports of bullying are not unheard of. Academic expectations may be higher, but pastoral support is not always so great. Class sizes tend to be bigger – 30 in Key Stages 1 and 4, 32 in Key Stages 2 and 3 are common.

Specialist help is not always available, as many teachers have received little or no training in SEN. Even a dedicated learning support assistant (LSA) may not be qualified. Having an LSA can mark a child out as different and alienate them from their peers. Learning support must be organised, allowing sufficient opportunity for a child to develop their skills and independence with access to the teacher, not just the LSA.

In some schools pupils are withdrawn from class, to work in a learning resource base or equivalent. This may provide security and specialist help for the child, but is teaching pupils apart from their peers, in a learning support unit or with an LSA, inclusion?

What's best is what's best for your child

Ultimately what seems to matter to parents of children with SEN is getting the best deal for their child, with the most appropriate provision, and having a choice available. The choice isn't necessarily static. Some parents may choose a special school early on, to get the added input, the early intervention that will help their child cope in a mainstream school later.

Others find that primary school is ideally suited for their child with SEN, but secondary provision isn't. At secondary level, demands can seem overwhelming to any child, let alone one with SEN: the additional organisational skills required; moving from class to class; seeing five or six teachers a day, none of whom may know you well; boisterous older children whose actions may be harmless, but to a tiny 11 year old seem fearsome; the size of the place; new subjects to grapple with.

Many schools are working to address these issues by special classes with fewer teachers for some children, the use of mentors, inclusive policies etc.

As provision changes, boundaries blur, a continuum of provision is talked of, rather than a straight choice between special and mainstream education. Additionally, a couple of thousand children are dual registered, spending part of their time in a special school and part in a mainstream.

Specialist or resourced/unit provision, a sort of halfway house, are increasingly popular options. Units and resourced provision often describe the same thing, though in some areas a unit operates as a mini-special school within a mainstream school, with resourced provision taking place mainly in the classroom, but with pupils being withdrawn to a resource for specialist input.

Units are usually attached to a mainstream school and tend to specialise in a particular SEN, perhaps in autism, or hearing impaired provision. Specialised facilities and specialists are attached to the unit, with help from teachers, therapists and others whose expertise is needed. Children will be based in the resource/unit, but may spend time in the mainstream classroom, and/or children from the mainstream may spend time in the unit.

It isn't only resourced provision that works this way; many special schools actively encourage their children to spend as much time as possible in a mainstream environment. Visits have to be carefully planned to suit the needs of the child and indeed the other members of the class the child will be integrated into. Admittedly some inclusion into mainstream simply plays lip service and the benefits to the child are neither tangible nor overt. At the other end of the spectrum some children have benefitted hugely from spending time in both special and mainstream schools. What is evident is that forays into either setting need to be carefully planned with motivations identified.

The one message that comes through loud and clear is: in the world of SEN there's no such thing as one size fits all. Flexibility and catering to the needs of the individual are paramount.

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Special educational needs and statementing

If a child has Special Education Needs (SEN), their school will increasingly, step by step, put in support or bring in specialist expertise to help with the difficulties they may have. This step-by-step approach is set out in the Special Educational Needs Code of Practice (available at www.teachernet.gov.uk). Parents or guardians should be consulted at every step, and be told about their child's progress.

School Action

This is the basic level of extra help, and could be:

- a different way of teaching certain things
- some extra help from an adult
- using particular equipment like a computer or special desk.

A teacher may decide to record these actions in an Individual Education Plan (IEP).

The IEP could include:

- what special or additional help is being given
- who will provide the help and how often
- what help I child could be given at home
- short-term targets to match the child's needs.

School Action Plus

If the child does not reach the targets set out in the IEP under School Action, their teacher or SEN coordinator (SENCO) should talk to parents about asking for advice from other people outside the school. These could include a specialist teacher, a behaviour specialist, an educational psychologist or a speech and language therapist. This kind of extra help is called School Action Plus.

If the help received under Action Plus does not seem to be meeting the child's needs and the school thinks they are showing cause for concern, the school should consider asking the local education authority to make a statutory assessment. This is a detailed investigation to find out what their child's special educational needs are and what special help your child needs. Parents also have a right to ask the local education authority for a statutory assessment, if they are not happy with their child's progress. They can do this even if the school does not agree with them and thinks that the child does not need a statutory assessment.

What is a Statement?

Once the local authority has carried out an assessment, they can decide to record the information they have in a statement of special educational needs (usually just called a 'statement'). This statement describes the child's special educational needs (SEN) and the special help they should receive.

How to apply for a statement

If the school is not applying on the child's behalf, parents or carers can apply on the Direct Gov website (www.direct.gov.uk), or through their local LEA. The application process for each individual county is different.

What is does a statement contain?

A statement of SEN is set out in six parts:

- part one gives general information about the child
- part two gives the description of the child's needs following the assessment
- part three describes all the special help to be given for the child's needs
- part four gives the type and name of the school the child should go to
- part five describes any non-educational needs the child has
- part six describes how the child will get help to meet any non-educational needs

What happens during the assessment?

Local authorities look at requests and tell parents (normally within six weeks) whether they will carry out an assessment. They also explain the assessment process.

Parents are sent a draft statement before the local authority writes a final version. It will be complete except for part four, which describes the type and name of school or education provided out of school. This is left blank so that the parents can say what educational provision they want for their child. Parents have time to review the draft statement and have the right to disagree with its contents. They have 15 days to comment and to say which state school, or non-maintained special school or independent school they want their child to go to.

Parents can also ask for a meeting with the local authority and they have another 15 days to ask for more meetings after that. Within 15 days of the last meeting, they can send in any more comments.

If parents would like more time to comment, they should talk to the 'Named Officer' at their local authority. This is the officer at the local authority who they will have been told is dealing with your child's case. The local authority must make the final statement within eight weeks of the draft statement. It will send parents a copy with part four filled in with the name of a school.

What happens after a child has the statement?

The local authority must review the child's statement at least once a year, checking their progress and making sure that the statement continues to meet their needs. The child's school will invite parents to a review meeting and ask them to send in their views on the child's progress over the past year. The review meeting looks at written reports and at the child's statement, and will see if it needs changing in any way.

Changes may be made, for example, if:

- the child's needs have changed significantly
- the local authority decides that different kinds of extra help are necessary
- the child has to move to a different school

Parents are also asked for their views on their child's progress. They may take a friend or an independent adult, and the child should be able to attend at least part of the meeting. After the meeting, the head teacher sends a report to the local authority recommending any agreed changes to the statement. The school also sends parents a copy of its report. This must be within 10 working days of the annual review meeting or by the end of term, whichever is sooner. The local authority may then decide to make changes to the child's statement. If the changes are to part four of the statement (changing the name of the school), parents have the same rights to choose a school as they had when the statement was made.

When an application for a statement isn't successful

If the local authority decides not to assess the child, it must write and tell parents and the school the reasons. If parents or the child's school still feel that more needs to be done, they should talk to each other. There are other ways the local authority can help the child, including getting outside help. The local authority should tell parents about local arrangements for sorting out any disagreement informally. Parents may also appeal to the Special Educational Needs and Disability Tribunal, an independent organisation.

Note: There might also be other children at the same school who have been statemented. It could be possible that some of the resources that the school receives for the other children could also be used to support the child with TS.

Where parents disagree with the statement

They should first speak to your Named Officer. It may also be helpful to contact the local parent partnership service, who can provide neutral advice and support. There is a right to appeal to the Special Educational Needs and Disability Tribunal (SENDIST) against parts two, three and four. The local authority will tell parents about the local arrangements.

What if a child has a statement, but is not getting the support set out in the statement or the support does not meet their needs?

If a child is not getting the educational support set out in their statement, parents should first check with the school to see why: for example, is it a short term problem due to a staff absence/equipment broken down? If they are not satisfied with the reasons but feel the support set out is correct, they should contact the Department for Children, Schools and Families at sen.queries@dfes.gsi.gov.

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Special educational needs, assessments and statements (Northern Ireland)

The law dealing with Special Education in Northern Ireland is contained in The Education (Northern Ireland) Order 1996 as amended by The Special Educational Needs and Disability (Northern Ireland) Order 2005 (SENDI). The Department of Education has provided guidance for Education and Library Boards and schools in the form of a Code of Practice on the Identification and Assessment of Special Educational Needs and also a Supplement to the Code of Practice, effective from 1 September 2005. To request a copy of the Code of Practice, call 028 9127 9939, or write to Special Education Branch, Department of Education, 43 Balloo Road, Bangor, Co Down, BT19 7PR

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Additional support needs and co-ordinated support plans (Scotland)

The Education (Additional Support for Learning) (Scotland) Act 2004 introduces the term 'additional support needs' and places a duty on education authorities to give extra help in their schools to all children and young people with additional support needs.

For further information visit the Scottish Executive Schools Directorate website: www.scotland.gov.uk/Topics/Education/Schools/welfare/ASL

The Act is available from <http://www.opsi.gov.uk/legislation/scotland/s-acts.htm> or from Her Majesty's Stationery Office, Tel 0870 606 5566.

The Code of Practice is available from www.scotland.gov.uk/Resource/Doc/57346/0016754.pdf

'The parents' guide to additional support for learning' from Enquire, containing more in-depth information and case examples can be accessed at www.enquire.org.uk/enquire/pdf/parents-guide-to-asl-2006-01.pdf. Contact Enquire on 0845 123 2303.

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Disability discrimination and reasonable adjustments

Disabled pupils or students at school or in higher or further education, or prospective pupils or students who think they have been discriminated against may be able to challenge this under the Disability Discrimination Act (DDA) 1995.

The DDA requires schools not to treat disabled pupils 'less favourably' and to make 'reasonable adjustments' to ensure that disabled pupils are not placed at a substantial disadvantage.

It is against the law for schools providers to discriminate against pupils in these areas:

- admissions (including placing requests)
- the curriculum, teaching and learning and other services which are provided wholly or mainly for students – including trips and outings, sports, leisure facilities and meals, libraries and learning centres, work experience and student accommodation
- by excluding them from an education institution or course.

What counts as a disability?

The DDA defines disability as a "physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities." In this context, 'substantial' can be interpreted as 'more than minor or trivial' and a 'long term adverse effect' is understood as an adverse effect that has lasted or is likely to last for at least 12 months.

Discrimination in education may take two forms: less favourable treatment of a disabled child, which the school cannot justify, and failure to make 'reasonable adjustments' to ensure the child is not at a substantial disadvantage, compared with others.

Factors that might contribute to a child being disadvantaged include:

- Time and effort that need to be expended by a disabled child
- Inconvenience
- Indignity or discomfort a disabled child might suffer
- Loss of opportunity or the diminished progress that a disabled child might make.

In deciding whether an adjustment is reasonable, these factors have to be weighed against the financial and practical implications of the adjustment, and a school's responsibility to maintain academic and health and safety standards and protect the interests of other pupils.

For more information on the DDA in schools, you may wish to contact the Equality and Human Rights Commission or the Independent Panel for Special Education Advice (see page 22 for contact details).

© Equality and Human Rights Commission, (www.equalityhumanrights.com), 2008

GLOSSARY

Anxiety - Can show as sleep difficulties, tension habits, motor unrest, phobias, worries, poor concentration, or panic attacks.

Attention Deficit Hyperactivity Disorder (ADHD) - A disorder characterised by an impaired ability to regulate activity level (hyperactivity), attend to tasks (inattention), and inhibit behaviour (impulsivity). For a diagnosis of ADHD, the behaviours must appear before the age of seven, continue for at least six months, be more frequent than in other children of the same age, and cause impairment in at least two areas of life (school, home, work, or social function). Adults too may show signs of ADHD such as overly impulsive behaviour and concentration difficulties.

Cognitive Behavioural Therapy (CBT) - A psychological treatment for mental health conditions. Treatment usually takes between eight and twenty sessions. It is a combination of cognitive therapy, which can modify or eliminate unwanted thoughts and beliefs, and behavioural therapy, which can help to change behaviour in response to those thoughts. CBT is based on the assumption that most unwanted thinking patterns and emotional and behavioural reactions are learned over a long period of time. The aim is to identify the thinking that is causing the unwanted feelings and behaviours and to learn to replace this thinking with more positive thoughts. The therapist does not focus on past events (such as childhood) but focuses on current difficulties at the present time. The goal is to teach new skills and new ways of reacting.

Co-morbidity - Presence of more than one disease or health condition in an individual at a given time. Obsessive Compulsive Disorder and ADHD are often co-morbid with Tourette Syndrome.

Conduct disorder - This can show itself as persistent and repetitive lying, stealing, truancy, starting fires, vandalism, fighting, or cruelty to animals.

Copropaxia and coprolalia - Copropaxia means making obscene or otherwise unacceptable movements or gestures. Coprolalia means using obscene or unacceptable language. This may involve swearing (though only 10-15 per cent of people with TS have coprolalia) or racist remarks. Coprolalia can cause serious problems at school, in society and at work, and it is particularly sad that the words uttered usually bear no relation to the true feelings of the person saying them.

Depression - Clinical depression is a common psychiatric disorder, characterised by a persistent lowering of mood, loss of interest in usual activities and diminished ability to experience pleasure. Depression should always be taken seriously. It is treatable and medical advice should be sought. In TS depression is most commonly seen in people with severe tics, sleep disturbances or OCD.

Echophenomena - Repeating other people's words is echolalia and other people's gestures is echopaxia. It is common in TS.

Epidemiology - The study of diseases or conditions in human populations and the factors that influence their incidence and prevalence

Full Blown Tourette Syndrome – Although this term implies that the TS cannot be developed any further, it is used to describe the middle level of severity of TS. This can be misleading, as the severity of TS can increase to become 'Tourette's Plus'.

Inappropriate sexual behaviour - This usually involves touching the person's own or other people's genitals.

NOSI - Non-Obscene Socially Inappropriate behaviour. It falls short of swearing, but involves saying or doing things that are socially unacceptable, for example personal remarks for instance about height, weight or facial features.

Obsessive Compulsive Disorder (OCD) – An anxiety disorder characterised by repeated intrusive thoughts and associated ritualised behaviours intended to alleviate that anxiety. Examples include touching an object with one hand after touching it with the other hand to 'even things up' or repeatedly flicking the light switch on and off. In more serious cases, the obsession may be around sexual, violent, or religious themes. Compulsions typically include checking, ordering, counting, repeating, getting things 'just right' or symmetrical, or forced touching which is a different spectrum from the symptoms of 'pure' obsessive compulsive disorder.

Paliphenomena - Similar to echophenomena but involves the person with TS repeating his or her own words and actions such as "Hello, I came here by bus bus bus bus".

Prevalence – The proportion of cases in the population; calculated by dividing the total number of cases in the population by the number of individuals in the population, eg one per cent of school children are affected by TS.

Pure Tourette Syndrome – TS with no co-morbid features.

Rage attacks - Frightening and destructive violent outburst, often without provocation or disproportionate to the trigger. Once begun, a rage attack has to be left to run its course. Rage may be linked to tic suppression.

SIB - Self-injurious behaviour. It includes punching and slapping the head, face or body, or scratching or sticking sharp objects into the body, including the eyes. It can be an obsessional behaviour.

Sleep Disorders - A group of syndromes characterised by disturbance in the patient's amount of sleep, quality or timing of sleep, or in behaviours or physiological conditions associated with sleep. These include frequent awakenings or walking or talking in one's sleep. Fairly common among people with TS.

Tourette Syndrome Plus (Tourette's Plus) – One of the proposed sub-types of TS, which includes ADHD, OCB or OCD, Self-Injurious Behaviours. This sub-type would also include TS patients with depression, anxiety, personality disorders, Oppositional Defiant Disorder, Conduct Disorder and any other learning problems.

Verbal and non-verbal IQ - IQ is usually split into two parts:

- intelligence that depends on verbal reasoning using language eg digit span, vocabulary, comprehension, verbal maths
- intelligence that depends on other areas like visuospatial ability eg solving physical puzzles, written maths.

Nonverbal IQ is also called performance IQ.

Waxing and waning – Term commonly used to describe the fluctuations in tic severity with TS. Tics can worsen (wax) and lessen (wane) with a frustrating lack of predictability.

Further information

Advisory Centre for Education (ACE)

www.ace-ed.org.uk

0808 800 5793

1C Aberdeen Studios
22 Highbury Grove
London N5 2DQ

Beatbullying

www.beatbullying.org

Rochester House
4 Belvedere Road
London SE19 2AT

Bullying UK

www.bullying.co.uk

Windsor House
Cornwall Road
Harrogate
North Yorkshire HG1 2PW

Department for Children, Schools and Families

www.dcsf.gov.uk

0870 000 2288
01928 794274 - Textphone/Minicom

Sanctuary Buildings
Great Smith Street
London SW1P 3BT

Equality and Human Rights Commission

www.equalityhumanrights.com

England

0845 604 6610 (0845 604 6620 - England textphone)

Equality and Human Rights Commission Helpline
Freepost RRLG-GHUX-CTRX-
Arndale House, Arndale Centre
Manchester M4 3EQ

Wales

0845 604 8810 (0845 604 8820 - Wales textphone)

Equality and Human Rights Commission Helpline Wales
Freepost RRLR-UEYB-UYZL
3rd Floor, 3 Callaghan Square
Cardiff CF10 5BT

Scotland

0845 604 5510 (0845 604 5520 - Scotland Textphone)

Equality and Human Rights Commission Helpline Scotland
Freepost RRLG-GYLB-UJTA
The Optima Building
58 Robertson Street
Glasgow G2 8DU

The Good Schools Guide

www.goodschoolsguide.co.uk

020 7801 0191

3 Craven Mews
London SW11 5PW

Independent Panel for Special Education Advice (IPSEA)

www.ipsea.org.uk

0800 018 4016

6 Carlow Mews
Woodbridge
Suffolk IP12 1EA

National Parent Partnership Network

www.parentpartnership.org.uk

020 7843 6000

8 Wakley Street
London EC1V 7QE

Special Educational Needs and Disability Tribunal (SENDIST)

www.sendist.gov.uk

SEN helpline: 0870 241 255555, Discrimination line: 0870 606 5750

Procession House
Ludgate Hill
London EC4M 7JW

Further reading

For more information about TS, you may wish to read the following books:

About Tourette Syndrome

- 'Tictionary: A Reference Guide to the World of Tourette Syndrome, AS, AD/HD and Obsessive Compulsive Disorder for Parents and Professionals' by Becky Ottinger.
- 'Tics and Tourette Syndrome: A Handbook for Parents and Professionals' by Isobel Heyman and Uttom Chowdhury.
- 'Tourette Syndrome - The Facts' by Mary Robertson and Simon Baron-Cohen*

Books for Teachers and Parents

- 'Anger Management Games For Children' by Deborah M. Plummer
- 'Disorganized Children: A Guide for Parents and Professionals' by Samuel M. Stein and Uttom Chowdhury
- 'Teaching the Tiger: A Handbook for Individuals Involved in the Education of Students With Attention Deficit Disorders, Tourette Syndrome or Obsessive Compulsive Disorder' by Marilyn P. Dornbush PhD and Sheryl K. Pruitt
- 'The Good Schools Guide to Special Educational Needs 2008' by Sandra Hutchinson
- 'Tourette Syndrome: A Practical Guide for Teachers, Parents and Carers' by Amber Carroll and Mary Robertson
- 'Kids in the Syndrome Mix of ADHD, LD, Asperger's, Tourette's, Bipolar and More!: The One Stop Guide for Parents, Teachers and Other Professionals' by Martin L., M.D. Kutscher, Robert R. Wolff and Tony Attwood

Books for Children and Teenagers

- 'Breaking Free from OCD: A Cbt Guide for Young People and Their Families' by Jo Derisley, Isobel Heyman, Sarah Robinson and Cynthia Turner
- 'Hi, I'm Adam: A Child's Book about Tourette Syndrome' by Adam Buehrens
- 'I Can't Stop: A story about Tourette Syndrome' by Holly L. Niner
- 'Quit it' by Marcia Byalick.
- 'Tic Talk: Living with Tourette Syndrome' by Dylan Peters.
- 'Touch and Go Joe: An Adolescent's Experience of OCD' by Joe Wells
- 'Why do you do that? A Book about Tourette Syndrome for Children and Young People' by Uttom Chowdhury and Mary Robertson.

* We understand a second edition is in preparation and will be published by Oxford University Press.

About Tourettes Action

www.tourettes-action.org.uk

Tourettes Action is the UK's leading support and research charity for people with Tourette Syndrome (TS) and their families.

Tourettes Action's vision is for people with TS to receive the practical support and social acceptance they need to help them live their lives to the full. Services are designed to offer support to people with TS throughout their lives and focus on delivering the appropriate information, practical help and opportunities for social contact at each stage: childhood, adolescence, and adulthood. Tourettes Action also works to educate and inform health and social care and other statutory agencies of the true nature of TS.

Some services are available only to members. Annual membership is £20.



Free Helpdesk

0845 458 1252

9am to 5pm, Monday to Friday.

help@tourettes-action.org.uk

Helpdesk

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

Thank you to all the people who allowed their advice and comments to be included in this leaflet. Particular thanks go to Lesley Anthony, Steve Barker, Justine Cload, Sally Fisher, Susan Hayter, Sandra Hutchinson, Dr Jeremy Stern and Zoe Streater.

Cover photography by Lorraine Swanson, using models.

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*understanding
the misunderstood

supporting people with TS through all
the stages of their lives

facilitating inclusion in society by raising
accurate awareness of TS

funding and facilitating research



For more information on Tourette Syndrome
and our services, see our website at
www.tourettes-action.org.uk or contact
our Helpdesk by calling **0845 458 1252** or
emailing **help@tourettes-action.org.uk**.

Tourette Syndrome (UK) Association
trading as Tourettes Action
A Company Limited by Guarantee
registered in England no.: 2613993
Registered office:
Southbank House, Black Prince Road,
London SE1 7SJ
Registered charity no.: 1003317

Cover photography by Lorraine Swanson, using models.