

The following article was published in
SEN Magazine
the UK's leading magazine for special educational needs



For a **FREE** trial copy of SEN Magazine, visit:
www.senmagazine.co.uk/freetrial

SEN Magazine Ltd. Chapel House, Shawbridge Street, Clitheroe, BB7 1LY
Tel: 01200 409800 Fax: 01200 409809 Email: subscribe@senmagazine.co.uk

Understanding Tourette's

Suzanne Dobson examines the facts about this often misunderstood and socially debilitating condition

Tourette's syndrome (TS) is characterised by multiple tics and must include both vocal and motor tics which are defined by being both involuntary and repetitive. It usually starts between the ages of five and seven, but this need not always be the case. Symptoms are often most severe at the age of eleven which, unfortunately, coincides with the transfer to secondary school.

Three times as many boys as girls have TS and in 88 per cent of people it is associated with other conditions, usually obsessive compulsive disorder (OCD) and attention deficit hyperactivity disorder (ADHD). The most commonly portrayed symptom of TS, involuntary swearing or coprolalia, only affects one person in ten. The less well known symptom of echolalia (repeating what has just been said) affects similar

Research tells us that worldwide one child in a hundred has Tourette's syndrome

numbers. It is hard to say which of the two is most difficult to cope with in the classroom, but both are frequently used by peers as an excuse for humour.

TS is a neurological condition and is therefore not linked to intellect, so students' academic ability is the same as for any other group of children. It is still not clear why TS occurs but we do know that it has a strong genetic link, so you can often identify someone else in the extended family that also has TS. A link has been noted between streptococcal infections and the sudden and often dramatic onset of TS, although this is still controversial.

Research tells us that worldwide one child in a hundred has TS at some level, and that around 300,000 children and adults in the UK have TS. However, anecdotal evidence suggests that these numbers are under reported.

TS varies in severity from mild/simple tics, perhaps a sniff and shoulder shrug, to severe/complex TS with expansive tics which cause pain and distress to the person with TS and frighten or disconcert others. Such tics can be very physical involving jumping, twirling and loud vocal noises. Tics can be both environmentally induced and can



become worse with stress or boredom. They may also be suggestible, in that something seen or heard can trigger a previously unseen tic. They can also improve when the individual is absorbed in a task, especially sport, music or other artistic endeavours.

There is no specific drug treatment for TS, although neuroleptic or antipsychotic drugs are sometimes used, as well as those used for OCD and ADHD. However, drugs are not the only way forward and cognitive behaviour therapies have proved to be successful.

Tics can occasionally be suppressed for short periods and often students try to suppress them in school, not only to appear to be the same as everyone else but also to try not to aggravate their teachers. This is no simple matter and children with TS describe trying to control their tics at school as being very difficult and stressful. One young man described the feeling as like blowing up a balloon; all day long it gets bigger and bigger and tighter and tighter and when they get home it explodes in a mass of huge tics and movements.

This often leads to conflict over homework, where either the child is too tired from suppressing all day or their tics are so bad that writing and sitting are still impossible. This can look like a very different child to the one who has been in school all day. Indeed, parents sometimes report that teachers tell them that the child is fine at school and that something must be wrong at home. This is not the case. Nothing is wrong either at home or school; it is just a consequence of trying to suppress TS tics. Of course, while the student is suppressing their tics, they don't have much mental capacity left to concentrate on lessons.

While the student is suppressing their tics, they don't have much mental capacity left to concentrate on lessons

So what strategies might help a child with TS? As we know, teachers and employers have responsibilities under the Disability Discrimination Act (1995) to make reasonable adjustments to meet the needs of all people with SEN, and there are a number of ways to make life easier for students with TS.

It is crucial for teachers to help all students understand what TS is and that it certainly is not funny. Then you need to decide how to manage your class regarding TS. Make it clear that whilst you may ignore some odd noises, movements or indeed words and phrases from your student with TS, this is not going to be the case for the whole class. When tics get too bad, the well understood time out card may be useful, and it is important to discuss and agree with the student what they need and where they can go to let off tics.

TS tends to be unique to each child, so different approaches may be needed for different children. A parent recently told me that her son's tics were triggered by flashing lights and that this caused particular problems in the run up to Christmas when classroom lights were flashing on and off more than usual. The lights had triggered her son's tics and he had been sent home five times in a week, causing much distress to both child and parent. When she spoke to the teacher about how to manage this

problem, the teacher did not understand how TS could be triggered by lights. As the mother pointed out, if her son had epilepsy, it would all have been very different.

Parents probably know more about their child's TS than anyone else, and they can be your best partner in making education work. Exam time can be doubly stressful as, on top of all the usual stresses, tics often increase at such times. It is sensible to make alternative arrangements for a separate room for the child. While this can seem like a resource intensive approach, it will help both the pupil with TS and the others taking their exams.

For 50 per cent of children with TS, their tics will abate in their late teenage or early adult years. While TS does not affect the intellect, the problems caused by the ineffective management of TS in the classroom can have a significant impact on the child's academic achievement and their ability to fulfil their potential. For the 50 per cent whose tics don't abate, the memory of a secure and supportive school environment will go a long way towards helping them to cope with one of the most socially debilitating of neurological conditions. **SEN**

Further information

Suzanne Dobson is Chief Executive of the charity Tourette's Action:

www.tourettes-action.org.uk