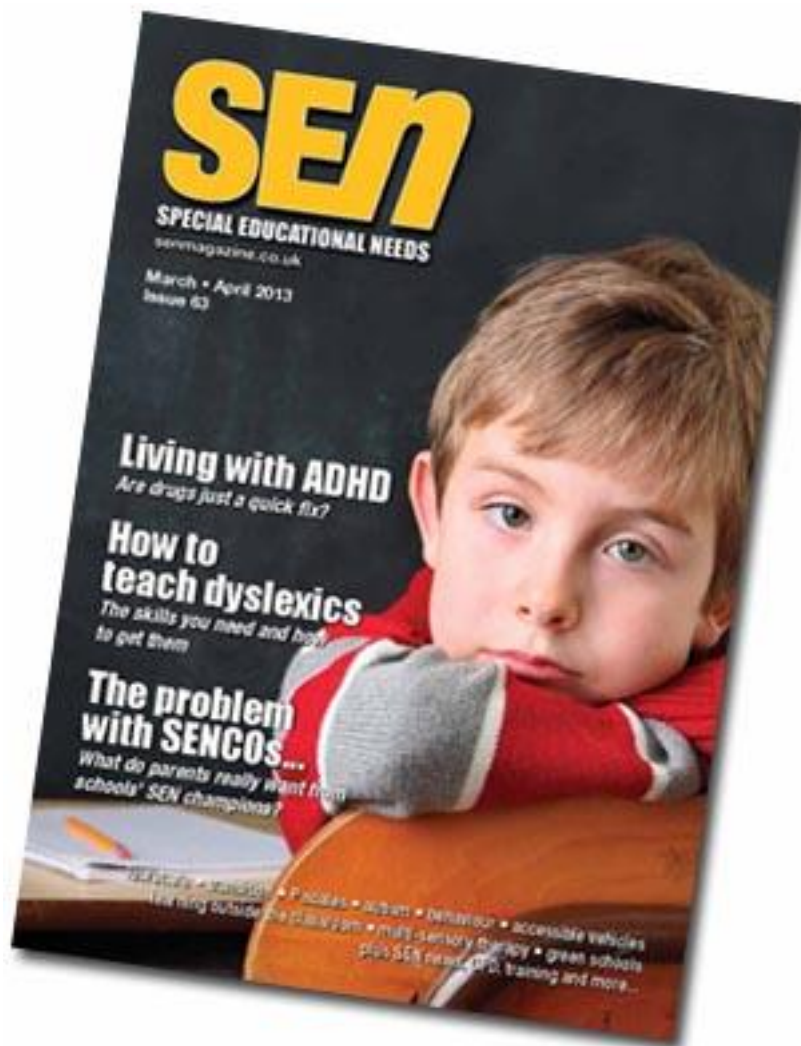


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On the tic

Suzanne Dobson looks at how Tourette's affects pupils and what schools can do to help

Tourette's syndrome (TS) is an inherited neurological condition. One school child in every hundred will have TS severe enough to be diagnosable by a specialist. As with many neurological conditions, boys are three to four times more likely to have TS than girls.

The key feature of TS is tics: involuntary and uncontrollable sounds and movements. TS is usually first diagnosed at around the age of seven years, although tics may be present before this time, and usually is at its worst between the ages of 12 and 13. For 50 per cent of people, symptoms will start to disappear by 18. It is important to realise that these symptoms are chronic (long-term) and for many people they are physically painful or damaging. For the majority of people living with TS, they are

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also exhausting. At the milder end of the spectrum tics may go mainly unnoticed but at the severe end, the symptoms are extreme and the social, educational and economic effects are serious.

The popular view of TS, that everyone with TS swears uncontrollably, is untrue. In fact, only one in ten of those with TS have coprolalia (the swearing tic), and only a few people have copropraxia (making rude gestures).

The other main problem-tics fall under the heading of non-obscene socially

inappropriate (NOSI) behaviour, where people with TS have a compulsion to do or say the wrong thing, which may be socially unacceptable – for example, touching something or someone they should not touch, or making an insulting comment.

Involuntary action

It is important to remember that the words people with TS articulate as tics do not reflect what they are thinking. In fact, people with TS are constantly surprised, embarrassed and upset by the words and phrases they use, as they have no warning about what they are going to say. This is perhaps the most difficult concept to cope with in school. Occasionally, tics are so apposite that no-one can believe that the phrase wasn't meant, and people



Careful classroom management is needed to keep classmates' mirth in check when a pupil tics.

feel targeted by the comments. So it is essential that all school staff understand that the young person is not using their TS to say just what they are thinking. We do not yet understand quite why the TS brain alights on particular words and phrases but perhaps one day we will understand this complex mechanism.

Echolalia (or palilalia) also causes problems for children with TS, mainly with those in authority, as this tic involves repeating what someone else, or even the person with TS, has just said. As you might expect, this can cause great mirth in a classroom setting, and confident classroom management is the best antidote. Understanding the unusual nature of TS tics and explaining them to the class is crucial. Make sure the other pupils understand that you do not expect them to join in, and that you want them, as far as possible, to ignore both palilalia and NOSI behaviours.

With younger children, it is often a good idea to include mum in explaining how TS works, but older children are often keen to explain this themselves. Schools report that this has been very successful in improving relationships within the class, minimising disruption and improving learning.

Over 85 per cent of people with TS have more than just tics. Additional comorbidities include obsessive compulsive disorder (OCD) and/or attention deficit hyperactivity disorder (ADHD). People living with TS may also suffer from rages.

There is no cure for TS and no specific medication; treatment is on a patient by patient basis. The standard treatment for TS is the use of neuroleptics; these are mainly used to treat psychosis, even though there is no established link between TS and psychosis. Currently, the most successful treatment for TS is cognitive behaviour therapy, but access to this type of therapy in the UK is very limited. There is little evidence for other non-drug treatments. While parents

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and children are often interested in the influence of diet, we have little reliable data so far.

Practical solutions

While people with TS exhibit the same IQ range as the population as a whole, their TS will often make learning harder. Constantly ticcing or trying to suppress tics is exhausting and, depending on the tic itself, may be physically debilitating. A recent study undertaken by Tourette's Action and the University of Nottingham, which will be reporting in spring, is looking at the psycho-social aspects of school for post-11 pupils. It is becoming clear that homework is particularly difficult for many with TS. Not only are they exhausted by their tics but also home is where they can tic freely. This means that concentration is often impossible, and handwriting or even using a computer is difficult.

This can cause a great deal of conflict between home and school; teachers often comment that something must be wrong at home, as the child doesn't tic like that in school. If you have a child for whom this is a particular difficulty, it may be a good idea to discuss whether a small reduction in the exam load, or allowances over homework, would help. It is important that those who have the potential for further education are not prevented from achieving this just because it is usual to take eight or nine exams.

It is also helpful to provide children with a time out card, allowing them to leave the classroom if their tics are particularly troublesome. It is particularly important if you are teaching a child who has rage attacks that they are allowed

to go to a safe space to calm down. The most futile activity is to ask a child with TS to stop ticcing. Not only is this largely impossible, but the added stress is likely to exacerbate the tics.

Many with TS have real difficulty with impulsivity and tend to act before they think. While students must understand that certain behaviours are unacceptable in school, it also important that any sanctions reflect the inability of the student with TS to easily control this.

Poor concentration and feelings of low self-esteem are also common problems for people living with TS. It can be helpful for a teaching assistant to make brief checks that the student understands what is going on in class and is on track. For some people living with TS, chewing gum helps them to keep concentration and reduce tics. Although this may not be a popular suggestion within school, it may be worth considering for those whose TS is particularly difficult or problematic. For younger children, fiddle toys, such as stress balls and tangles, can be helpful.

Perhaps the most confusing thing about TS is how the tics change both in severity and nature over a very short period of time. You may have just got used to one tic when it is replaced by another, or an additional one is added. The key thing is to understand exactly how TS affects the particular individual concerned. Make sure you have a good rapport with the parents; they will know that something has changed and be able to forewarn you. **SEN**

Further information

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www.tourettes-action.org.uk