

# Tourette Syndrome in secondary schools

December 3 2013, by Emma Thorne

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Secondary school can be a stressful enough time for any teenager, but for those living with Tourette Syndrome (TS) their neurological condition can present a whole new set of challenges.

Now a study led by researchers at The University of Nottingham has given a unique insight into the impact of TS on secondary education by talking to parents, teachers and, for the first time, the young people themselves.

As a result of the study commissioned by the national charity Tourettes Action, and funded with £335,751 by the Big Lottery, the powerful words of young people with TS are being used to train teachers on how to recognise and respond to the condition.

## Huge impact

Professor Georgina Jackson, who led the research in the University's Division of Psychiatry and Applied Psychology, said: "This study is the first to address the experiences of young people with TS from their own point of view.

"TS is often seen purely in terms of the tics that affect many with the condition but for these children there is often an awful lot going on inside their heads too, often related to anxiety over how to control their visible symptoms.

"Like any teenager, they are keen to fit in and the quality of their school

experience and the development of friendships at this important stage of their life can have a huge impact on how they adjust to living with the condition in adulthood."

TS is an inherited [neurological condition](#) affecting as many as one in 100 school-age children. The condition is characterised by tics—involuntary, uncontrollable and repeated sounds and movements—which start in early childhood and peak from the age of 11 through the teenage years.

## **Symptoms pose challenges**

These tics can change in type, severity and frequency and can be temporarily delayed with effort—meaning that pupils with TS can present a changing picture and there may be periods when their tics become more severe and disruptive in the classroom.

This can pose a challenge for teachers, many of whom have little experience of the condition, in recognising TS symptoms rather than perceiving a child to be deliberately disruptive or 'naughty'.

The study recruited 35 young people with TS through Tourettes Action and through mainstream secondary schools in the East Midlands, West Midlands and Yorkshire.

Academics interviewed each young person, one or both of their parents and one or two members of staff from their school—which included teachers, teaching assistants and Special Educational Needs Coordinators (SENCOs).

They were asked to talk in detail about how having Tourette syndrome affects them in school, including their classwork, behaviour and relationships with others.

The three challenges more frequently reported by the young people were problems concentrating in class, unhelpful responses by school staff and teasing and bullying by other students, such as name-calling and mimicking tics.

Some also reported that homework, examinations, writing, anxiety and managing anger were additional challenges for them. For example, severe movement tics involving the hands can cause difficulties with completing homework and with handwriting. Vocal tics, such as making sounds or saying words out loud could sometimes attract unhelpful responses from school staff, such as being told off.

The young people reported significantly more victimisation than normal but relatively few staff were aware that their students were being teased or bullied.

## **Practical guidance**

The results of the study have been used to devise a new training package for [secondary schools](#), which covers the basics of TS, its symptoms and how it's diagnosed as well as common misconceptions—for example TS does not affect IQ and is not a learning disability but can be a barrier to learning.

It goes on to explore the issue of tics and outlines the social, emotional and economic impact of TS and the challenges facing those with the condition. Quotes given by the [young people](#) in the study are used to illustrate what it is like to have Tourette Syndrome in school and to help staff to better understand the day-to-day reality of the condition.

Most crucially it also offers practical guidance to staff on supporting pupils including better communication with pupils and parents, greater recognition and respect for the management strategies that pupils use to

control their condition and greater awareness of when teasing and bullying may be taking place.

In addition, it also advises not to punish pupils for behaviour which they cannot help.

The academics have delivered the training package to around 80 school staff to-date and are currently recruiting more schools interested in taking advantage of the resource.

It will also be used by Tourettes Action to update the information materials on their website which are aimed at children, their families and their teaching staff.

Provided by University of Nottingham

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