

# Tourette Syndrome in school – a parent's guide



## What is TS?

Tourette Syndrome (TS) is an inherited neurological condition. It affects one school child in every hundred (same prevalence as Autism) and is more common amongst boys (75% are boys). Over 300,000 children and adults are living with TS in the UK. When we say 'inherited' that's not to say the parents will have TS but rather that there may be a possibility someone in the family may be somewhere on the spectrum of one of the associated conditions. These will be discussed in more detail later. You can find out more about the causes of TS on [www.tourettes-action.org.uk/21-causes.html](http://www.tourettes-action.org.uk/21-causes.html).

In order to meet the diagnosis criteria for Tourette Syndrome, tics (involuntary sounds and movements) must be present for at least 12 months so it's very important that you record as much evidence as you can before you a specialist. You can find out more about getting a diagnosis on [www.tourettes-action.org.uk/20-getting-diagnosed.html](http://www.tourettes-action.org.uk/20-getting-diagnosed.html) and seeing a specialist on [www.tourettes-action.org.uk/resource-68-guide-to-seeing-a-specialist.html](http://www.tourettes-action.org.uk/resource-68-guide-to-seeing-a-specialist.html). Classically for TS, tics also have to be seen as being changeable/wax and wane (a term often used to describe the coming and going of tics). TS is a spectrum condition ranging from mild to severe symptoms. Individuals may move across the spectrum over time or in response to environmental factors.

Environmental factors are huge for a child with TS and can be big triggers to their tics. Many children with TS are reported to have sensory issues which will all play a part in the levels of anxiety that they experience, which in turn may trigger certain tics and behaviours. Sensory issues may appear with change of environment. Changes in rooms, temperature, smell of a room or person, touch

of a piece of furniture or stationery, sound of a person's voice, feel of clothing or a chair they are sitting on are all possible reasons for a noticeable increase in tics. Tics typically start around the age of 6/7 years and tend to peak around early adolescence. Hormones play a big part in TS. At around the age of 7 or 8 some neuro-developmental changes seem to take place in children which is why we can see a change in tics at around this time and again as a child enters puberty in the early teenage years. In approximately 50% of cases tics can lessen by adulthood.

TS can be initially triggered by emotional events. Emotional events have been reported to trigger TS in a child that is already potentially genetically determined to acquire TS. These could be things such as a change in circumstances at home, a loss of a loved one, a medical trauma, etc.

Tics can be increased by stress, anxiety, excitement, hunger, tiredness, sensory changes and decreased by things such as exercise, distraction or deep concentration.

## Destroying the myths about TS

TS is often misunderstood as a condition in which everybody swears, or says socially inappropriate things. Although it is true that 'coprolalia' – the clinical term for involuntary swearing – is a symptom of TS, it only affects a minority of people. 90% of people with TS do not have coprolalia. It's very important that schools get training to fully understand TS so that they can fully understand their pupils and we can be sure children are not being sanctioned for their tics. You can find out what support is available for schools on [www.tourettes-action.org.uk/62-teachers.html](http://www.tourettes-action.org.uk/62-teachers.html).

### Having tics doesn't always mean Tourette Syndrome

Tourette Syndrome is on the spectrum of conditions known as Tic Disorders. Other conditions on this spectrum include:

**Provisional/transient tic disorder:** Vocal or motor tics that tend to be transitory. Tics only last a few weeks or months.

**Persistent/chronic tic disorder:** Vocal or motor tics that tend to persist rather than be transitory. Tics occur for more than one year.

**A tic disorder not specified:** Tics are present, but do not meet the criteria for any specific tic disorder.

To be classified as TS then both vocal and motor tics must be present but we can use the same strategies for tics as we do for TS.

### Common motor and vocal tics

	Motor tics	Vocal tics
<b>Simple</b>	<ul style="list-style-type: none"> <li>Eye blinking</li> <li>Eye rolling</li> <li>Grimacing</li> <li>Shoulder shrugging</li> <li>Limb and head jerking</li> <li>Abdominal tensing</li> </ul>	<ul style="list-style-type: none"> <li>Whistling</li> <li>Throat clearing</li> <li>Sniffing</li> <li>Coughing</li> <li>Tongue clicking</li> <li>Grunting</li> <li>Animal sounds</li> </ul>
<b>Complex</b>	<ul style="list-style-type: none"> <li>Jumping</li> <li>Twirling</li> <li>Touching objects and other people</li> <li>Obscene movements or gestures (copropraxia)</li> <li>Repeating other people's gestures (echopraxia)</li> </ul>	<ul style="list-style-type: none"> <li>Uttering words or phrases out of context</li> <li>Saying socially unacceptable words (coprolalia)</li> <li>Repeating a sound, word or phrase (echolalia)</li> </ul>

### Hidden tics

It's really important for schools to know that tics are not always just the obvious ones we can see or hear but there can be lots of hidden tics that children may be dealing with internally that others may not be aware of. These can often be the ones that are most uncomfortable. They are often mentioned as mental tics and can be tics such as visual tics (looking at shadows, counting objects) or intrusive

thoughts about harming themselves or others.

Two of the most difficult to understand are the thought and conversational/contextual tics.

An example of a thought tics could be where a teacher walks in the room and they are bald or smelling of body odour. A neuro typical child may also notice those features but would not say anything. A child with TS may find it hard to not vocalise this information as impulsivity can be extremely high, which can result in the overwhelming urge to vocalise their thought into words.

An example of a conversational/contextual tic could be, for example, if when telling a child to concentrate, they utter the words 'shut up'. If the teacher does not know the child well then this could appear like a genuine response and not a tic. However, teachers need to consider the fact that the child may just have an overwhelming urge to say the most inappropriate thing at this anxious time and may just come out with the very worst things they would be trying not to say. Thought tics are often something we all think but kids with TS can't always regulate these thoughts. It can be a bit like having a window into their soul.

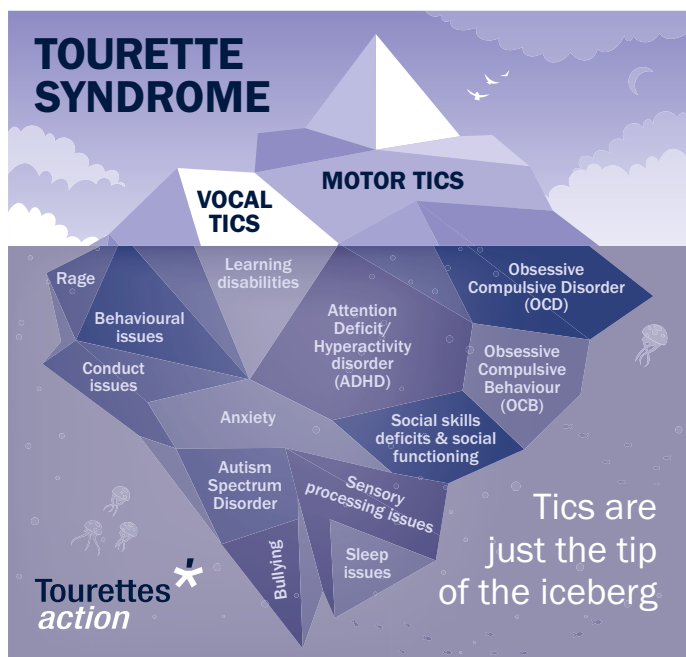
Suggestive tics can also be very hard to deal with in school. These can be the overwhelming urge to follow through inappropriate suggestions, e.g. don't run in the corridor, not talking in assembly or don't touch the fire door.

### Co-occurring conditions

It is rare to see a child with just pure TS. Approximately 85% of people with TS will also experience co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), Autism Spectrum Disorder (ASD), Anxiety, Sensory Processing Disorder (SPD) to name but a few. For many, the co-occurring conditions can be more challenging than the tics themselves.

This is really important for schools to know as it may not be their tics that are causing the main issues in school.

When we look at this visual below, there is no wonder why so many children with TS suffer from rage or with their mental health in general. To have so much going on can be very confusing for a child so teachers need to be very understanding of all the issues these children may be facing. You can find out about the more common co-occurring conditions on [www.tourettes-action.org.uk/74-co-occurring-symptoms.html](http://www.tourettes-action.org.uk/74-co-occurring-symptoms.html).



### Why might getting a diagnosis be important?

No parent wants their child to be ‘labelled’ but it is very important in the school setting that we get a correct list of diagnoses for a child in order to best understand them and support them.

We could use the analogy of a cake for this. The ingredients of a cake are like the elements of each diagnosis in a child. If we don’t understand all the different ingredients of a cake, then we can’t make its structure work. If we don’t understand all the elements of a child’s diagnosis, then we won’t be able to make sense of how they best learn at school. A better understanding of the child’s needs can ultimately lead to better support to be put in place at school for the child.

Not only does a correct diagnosis open things up for treatment options with medications and therapies, it also gives parents’ permission to parent differently. By this we mean that parents can often feel confused at why their children act differently to other people’s children but having gone through a diagnosis process it can give parents reasons and answers to many questions they may have had about their child’s behaviours for many years. With understanding comes acceptance and a sense of relief that someone else recognises what they are going through.

### After diagnosis

If a child is lucky enough to get a referral to CAMHS (Child and Adolescent Mental Health Service) and gain a diagnosis, this can open doors for them to gain better understanding and support.

Local support groups or online groups can be very important for both the child and their family members. It may be a chance for them to speak with other families and realise they are not on their own. Also, finding charities like Tourettes Action or more local charities can provide parents with knowledge of what’s around them to support them. Getting advice on local and national grant schemes, befrienders, discount cards etc. can all be very beneficial to families. Please contact our support manager Emma for more information about online and local support groups near you at [emma@tourettes-action.org.uk](mailto:emma@tourettes-action.org.uk).

It’s important to know that parents do go through a grieving process as they suddenly ask themselves questions like, ‘Will anyone else love my child like I do?’, ‘Will they ever get married?’, ‘Will they be able to hold down a job?’, ‘Will they be able to drive?’ The answer to all these questions is absolutely YES! With the correct support in place you will eventually learn and give yourselves permission to parent differently.

Psychoeducation is very important for the child. By this, we mean it’s important they know what TS is, how it affects them and ways in which they can help themselves. Sometimes we come across children that don’t wish their peers to know they have TS and even parents that don’t want people to know and that’s personal choice, but evidence shows that these children can often suffer with their mental health as a consequence of people around them not understanding or being able to help and support them. Evidence suggests that children need to embrace their differences and be proud of who they are and spread as much awareness as they can of their condition.

### Mental health

Tourette Syndrome is not a mental health condition but it can certainly affect a child’s mental health. Many children have been reported to have suffered from anxiety, rages, depression and even suicidal thoughts. Such symptoms can be made worse by factors like hormones, bullying and change.

The huge amount of stigma that surrounds TS often limits the confidence and self-esteem of those diagnosed, especially young people. Which is why it is so important for schools to be properly educated and have the right support in place so our children feel fully understood and accepted by the school community.

It’s always best to encourage a child to talk about their TS. It’s important that they understand what’s going on for themselves and, if possible, encourage them to share with their friends. Education and awareness is the key!

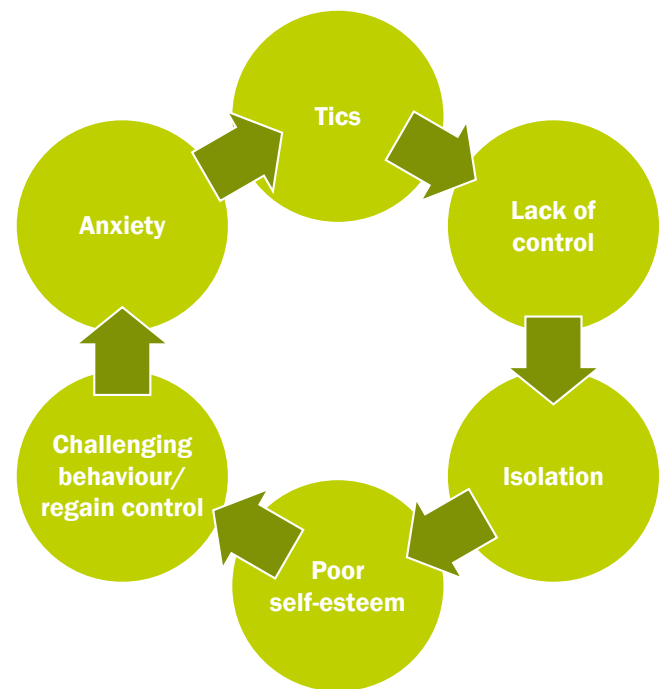
### Tics vs neuro-typical bad behaviour – the magical question

This is the main question that gets asked by teachers and support staff and the answer is there is always a reason for what appears to be ‘bad behaviour’. Children with tics can sometimes come across as being ‘badly behaved’ as tics can appear to be in context so it’s up to teachers to find out why they are displaying such behaviours. Consider this – It’s much easier for a child to come across as the class clown and be told off than it is to show their tics and appear to be labelled by friends as weird or strange. If teachers are ever unsure if something is a tic or negative behaviour, then we must always assume it’s a tic. It can be impossible at times to unpick if a tic is genuine but we would advise teachers to get to know the child rather than challenging and questioning them all the time. After an incident talk to the child and ask the child: What happened? Why do you think that happened? How can we help you next time?

Bad behaviour alongside TS can be a sign of the child trying to regain some control and distracting from their tics. Sometimes tics can fall into a negative cycle and it’s important to work out where best to break this cycle in order to support the child at school. The best place would be before the anxiety kicks in. Anxiety is a fuel to tics so we need to find out what the triggers are for the child that make them anxious in order to break this cycle. In order to do this schools must involve the child in some PUPIL VOICE sessions. Talk to the child. Discuss together what their tics are, what makes them worse and how they could help them.

### Should a child apologise for their tics?

It’s important to know that we don’t expect a child to apologise for having TS but we must certainly encourage



them to apologise and explain if their tics have upset anyone. Much like how we wouldn’t expect a child to apologise for being in a wheelchair but we would expect them to apologise if they accidentally bumped into someone with their foot plates.

### What makes an appropriate punishment/sanction/management strategy?

Consider the common sanctions delivered by lots of schools below. Think about the impact these punishments will have on your child:

- Sending a child out of a lesson
- Staying behind to finish work
- Take unfinished work home
- Missing play/PE
- Missing school trips
- Detentions
- Isolations
- Suspensions/expulsions

It’s worth bearing in mind that where reasonable adjustments are put in place for SEN children to support their learning, the same must be said for their behaviours and punishments too. It’s great that schools pride themselves that all their students are treated the same but we must remember that all children aren’t the same and should not always be treated the same as their peers. For example,

putting a child with mental health issues in isolation can be even more detrimental to their mental health.

Of course children with TS can still misbehave and it is important that attention is brought to this and dealt with appropriately but this may not be the same as their peers. Some SEN children can feel a big sense of injustice at times of negativity so it's very important that we give them time to reflect and talk to them as they may not even realise where they went wrong and why they are being told off. They may need more explanations than their peers. It's also very important that a child with any social communication issues has any intended sanctions sorted out the same day as the incident occurred, and not on a different day or end of the week. By then, the child will have moved on and may find it hard to merge the two situations together which in turn may cause anger and frustration.

Make sure if your child is receiving a punishment the teachers are clear about the situation and make sure a tic hasn't been mistaken for bad behaviour. Children with TS must not under any circumstances be told off for their tics.

### School refusal

School refusal is real. Schools often find it difficult to understand that in the case of children with SEN and specifically TS, it's not always a case of 'won't' but rather a case of 'can't' come to school. It's crucial to understand the underlying cause of the school refusal and in the case of TS, it's commonly seen as anxiety. Anxiety in children and school can be common but for children with tics, they may be worried about feeling different, being picked on, or having to answer questions about their tics to both friends and teachers. Mild anxiety is normal and as a one off it can be as simple as children needing to face their fears but this 'flooding' approach is not always the way. If a child with TS is refusing to attend school, then there will be reasons around that. A forced attendance approach is not effective with children with TS as it leads to increased anxiety which in turn can create increased tics and ultimately longer absence from school. Often the thing a child fears the most is what schools tend to set as an end goal – returning to school.

For children experiencing school refusal, we would recommend either a reduced timetable to start off with or some kind of gradual integration and a phased return to school alongside talking with the pupil and their family to find out the real reasons behind them not being able to



attend. If you are after more specific help around school refusal then please visit the charity 'Square Peg' on [www.teamsquarepeg.org](http://www.teamsquarepeg.org).

### Can tics be controlled?

Although tics are involuntary, many people are able to suppress their tics for a short time. It is quite common for children with TS to suppress their tics at school, yet families will notice a marked increase in their child's tics at home. This is why teachers may see less at school than parents do at home as home is a safe place where no judgment will be made. School is very structured with reinforcers that may make a child want to control their tics. In comparison, home life is more relaxed and therefore helps children to feel at ease with expressing their tics. You may have said to school 'my child tics loads at home', and yet at school they may not see many tics at all? Home is a safe, non-judgemental place where children can let out their tics, so even if there are no expectations to keep their tics in, you may find that some will try automatically if they have learnt the skills to do this and are happy to do so. In most cases, we find it is a much more pleasant experience for children if they feel comfortable enough to tic at school.

Tics are extremely difficult to suppress. If we expect children to suppress their tics, then this may have repercussions later. If a child has learnt to suppress a tic for a little while, it will come out eventually. It takes a lot of energy to suppress and can be very tiring. Unless however, a child has had access to some therapy and been trained to manage their tics in this way then they may have some success in this.

It can be extremely painful and uncomfortable to suppress a tic as this exercise will illustrate. Try not to blink and keep your eyes open for a whole minute. Eventually you will have to blink as the urge is too strong to control. How easy was it? How did it make you feel? This is similar to the feeling many people with TS report when they have to hold their tics in. The **premonitory urge** is similar to the feeling you may get when you have that urge to blink or feel a sneeze building up or have an awareness of an itch you need to scratch. This awareness of a tic coming is something that will be used and worked on if a person decides to try some CBT therapies. Therapeutic interventions do need a certain level of control to be applied and children need to be mature enough to take this on.

It’s very important to know that whilst a child is **ticcing** or **suppressing**, they will not be able to concentrate. Any work or input that is done during them ticcing or suppressing may need to be reinforced after on a one to one basis. These children may also be the ones highlighted by teachers that have not yet started a task or been able to complete or achieve the learning objective. Teachers may not recognise this as related to tics so it’s very important they are aware that this may happen before any sanctions are enforced.

### What therapies are available?

There are therapies that can help people with TS but a child has to be mature enough and aware enough to want to give this a go.

We do not recommend teachers try these out at school. These have to be carefully considered by the parents and delivered by trained therapists. You can find out more about available therapies on [www.tourettes-action.org.uk/71-behavioural-therapies.html](http://www.tourettes-action.org.uk/71-behavioural-therapies.html).

Below is a list of common ways that people use to help control their tics:

- Habit reversal therapy – finding a competing response
- Exposure response prevention – learning to suppress for periods of time
- Psychoeducation – learning and teaching as much as we can about TS
- CBIT – Comprehensive behaviour intervention for tics
- Social support
- Relaxation therapies
- Nutritional supplements
- Diet



### Medications

There are medications available for people that suffer with severe TS but it’s worth noting that most will come with side effects. Medication is usually a parents’ final decision after trying the above strategies and it’s a case of weighing up the TS symptoms against how bad the side effects are and how much relief this would offer a child. Side effects of medications can include tiredness, hunger, headaches, heart and liver complications and many more. More information on medication can be found on our website: [www.tourettes-action.org.uk/70-medication.html](http://www.tourettes-action.org.uk/70-medication.html).

### How can TS create a barrier to learning?

TS does not in itself affect IQ, but it can have a huge effect on a child’s ability to learn. For example:

- Concentrating on a lesson can be hard if a child is trying to suppress tics.
- Co-occurring conditions may get in the way e.g. ADHD (concentration), OCD (perfection), hyper mobility (tiredness in joints).
- Impulsive traits can manifest as calling out in class/ throwing/ripping.
- Hidden tics (thoughts, visual etc.)
- Disruption for others.
- Sleep – generally relaxing the body or bedtime rituals and routine.
- Medication – may make children tired which can affect their work.
- Feeling socially isolated from peers can also have a huge impact on learning.
- Motor tics of the eyes, head or neck may interfere with

reading and motor tics may also affect handwriting or the ability to write for prolonged periods of time.

- Motor and vocal tics may make a child reluctant to read aloud, ask or answer questions and even sometimes to ask for help. A child may be very anxious about reading out in class if they have verbal tics such as Palilalia whereby they may stutter or feel the urge to repeat their sentences over and over until they feel ‘just right’.
- Physical and vocal tics can be exhausting and sometimes painful for the child experiencing them, leading to tiredness and lack of enthusiasm.
- Children may come across as being disengaged in their learning when in fact this may be due to other TS related issues.

It’s really important schools work hard to help remove these barriers to learning that a child may face and put strategies in place to help them have full access to the curriculum and reach their full potential.

### Homework

Homework can be a big issue for parents and children with TS. Some children with TS have tics that make them very tired and just making it through the day at school can sometimes be enough without having to continue their learning at home. For other parents building up their children’s stamina can be very important especially when in high school and working towards exams. What we would advise is that teachers either differentiate the homework for the child or, if a child doesn’t want to appear different from their friends, then we advise teachers talk to the parent and allow you to differentiate the homework at home. Encourage your children to have a go but don’t put too much pressure on the child for it to be completed. Urge on quality rather than quantity. If there are 20 maths questions, then encourage them to try the first few.

### Excluding children from activities due to risk of harm

There may be times that school may feel that a certain trip or activity in school will not be safe for your child to attend. If for example, a child has a throwing tic and is going to be handling a boiling liquid in a science lesson, then the teacher may feel this situation may have the potential to cause the child harm to themselves or others. In cases such as these, it is important that the child in question is seen as having input into this decision and it is not seen as a punishment to be withdrawn from the activity. Schools should complete a risk assessment for the activity and involve the child as

much as possible as to the potential risks and the plan of action should these risks come into play.

### Executive functioning difficulties.

Executive functioning difficulties can be very common in children with TS. It may be that they need some extra support in the areas that they find difficult. You may notice some of these difficulties at home too.

## Executive functioning skills



**Planning** is the ability to figure out how to accomplish our goals



**Organisation** is the ability to develop and maintain a system that keeps materials and plans orderly.



**Time management** is having an accurate understanding of how long tasks will take and using time wisely and effectively to accomplish tasks.



**Task initiation** is the ability to independently start tasks when needed. It is the process that allows you to just begin something even when you don’t really want to.



**Working memory** is the mental processes that allow us to hold information in our minds while working with it.



**Metacognition** is being aware of what you know and using that information to help you learn.



**Self-control** is the ability to regulate yourself, including thoughts, actions and emotions.



**Attention** is being able to focus on a person or task for a period of time and shifting that attention when needed.



**Perseverance** is the ability to stick with a task and not give up, even when it becomes challenging.



**Flexibility** is the ability to adapt to new situations and deal with change.

Executive functioning is a set of mental skills that include three main areas:

- Working memory (keeping information in mind and putting it to use)
- Flexible thinking (see problems from multiple angles and find different ways to solve them)
- Self-control (ability to stop before you respond on impulse)

We use these skills every day to learn, work and manage everyday life. Difficulties with executive functioning can make it hard to focus, follow instructions, regulate emotions etc.



*How does this effect our children? What can this look like in school?*

- Paying attention and focusing
- Organising and planning
- Starting and completing tasks
- Shifting focus from one task to another

*How can we help improve children’s Executive Functioning?*

- Modelling good organisational skills
- Give them time to process
- Teach to pause and reflect before responding
- Use writing frameworks/task planners
- Keep expectations clear and consistent

You can find out more about executive functioning and how to help children on [childmind.org/article/helping-kids-who-struggle-with-executive-functions](http://childmind.org/article/helping-kids-who-struggle-with-executive-functions).

### How can school help children with TS – suggested strategies

Without training you may find a lack of knowledge and understanding in schools about TS so it may mean that you will be leading the way in educating them. Any good school should welcome the chance to learn about your child and how best they learn. With education comes greater understanding and acceptance for your child. You can download our free online teacher training to pass onto your schools on [www.tourettes-action.org.uk/resource-210-presentation-ts-in-schools.html](http://www.tourettes-action.org.uk/resource-210-presentation-ts-in-schools.html).

All children with TS are unique and will experience different tics, triggers and have varying needs but these are some basic strategies that should apply to most children with TS and what we would recommend teachers try first with the children:

- Approach the child and family to find out how their TS affects them and keep communication as open as possible.
- Try not to respond to tics, unless they really require a response e.g. danger/safeguarding of other pupils.
- Never single a child out in class because of their tics.
- Never punish a child for their tics.
- Make a personal passport/one-page profile all about the child to share with all teachers.
- Consider a careful seating plan.
- Consider giving the child a time out card/leave room.
- Make sure there is always a safe place for children to go and release tics if needed.
- Make sure children get regular sensory breaks/brain gym.
- Consider fidget toys. Distraction is a key with tics so this may help immensely.
- 5 minute earlier/later start time to the day to meet a member of the pastoral team and go through their timetable to make sure they have all the equipment they need for the day so we are not setting the child up to fail before they have even begun. This will help children with executive functioning difficulties too.
- Build a relationship with the child so they feel understood and safe.
- Use visual timetables to aid understanding. Knowing what’s coming up in the day to reduce any anxieties and feeling in control of themselves.
- Use feelings chart where needed.
- Scale down work amount not difficulty.
- Check understanding after class input.
- Scribe/laptop? Find out how best the child learns/ records ASAP. Encourage school to explore ways of recording your child’s work. It may be that their tics get in the way of their writing for many reasons. The sooner they find a way to best record their work, the sooner they will get into a consistent routine and this will support their ‘usual way of working’ if any further support or intervention is needed.
- Awareness assemblies are an effective way to educate other pupils (celebrating differences). A whole school approach to understanding Tourette Syndrome can really help a child to feel accepted and understood. You can download our peer presentation to give to your school on [www.tourettes-action.org.uk/resource-239-what-is-ts-a-presentation-for-young-people.html](http://www.tourettes-action.org.uk/resource-239-what-is-ts-a-presentation-for-young-people.html).



- Consider alternative therapies to help reduce anxieties such as art, music or Lego therapy to aid self-expression.
- Invest in good quality nurture programmes and Emotional intelligence training to help promote well-being, self-esteem and positive mental health such as: ELSA – (Emotional Literacy Support Assistance) – primary, MISP – (‘Mindfulness in schools’ project 7 – 11) and JIGSAW – secondary schools.
- Research and access any free alternative provision in your area that work with schools for example, Intensive Planning Team or Learning and Behaviour team.

## Safeguarding

This is a topic schools may need to consider very carefully regarding a child with Tourette Syndrome. Some schools feel that a child may not be safe in school due to the nature of their tics, e.g. self-harming or may need to consider the safeguarding of the other pupils if, for example, the child with TS has any swearing tics. Lots of parents say that schools cannot meet the needs of their child or that they can’t have the child in school because of safeguarding theirs and other children. Below are two examples of things you can suggest to school which may help your child stay in school. These are both examples where coprolalia may be apparent. We want to keep our children in school as much as we can so alternatives to these situations are much better.

- 1 Schools may want to consider having a staff member in their pastoral team that has had extensive TS training and will be available for both pupils and staff to go to if they feel upset by any comments made. Even though pupils and staff will know this is an involuntary condition it may still be upsetting to hear some verbal tics especially if they are personal.
- 2 Sending a letter home to all parents may be worth considering (with your permission) informing all parents that they have a child in school with TS and that they will provide an information event where they can come and find out more about the condition and how they will be supporting this in school. It’s important other parents know that the school will be celebrating all differences in their school and feel open and happy enough to talk about it with other parents that may have trouble understanding.



## Consistency is the key

It is very important that whatever strategies and expectations schools put in place are clear and consistent both on expectation on output of work and behaviour. Pupil voice is so very important in this as expectations need to be very clearly explained to the child and fully understood for them to be able to have a chance at succeeding.

Praise and encouragement for small achievements is very important for all children and schools should be seen to be giving praise where possible. A recent study said that teachers who use lots of praise saw a 30% increase in good behaviour and found that pupils were more engaged. Praise and rewards are proven to be very effective even for secondary age. It doesn’t matter how small the reward; it can be very effective in giving children encouragement.

## Transition

We know that transition is a tricky time for all children but especially those children with TS. We know environmental factors play a huge part in anxiety as lots of sensory factors such as change of room, lighting, smell etc. can trigger tics. Transition is a very anxiety driven time for all children but with tics added to the mix, children will have added worries about their tics, friendships and questions that people may ask them.



Tics often worsen during the transition to secondary school or even just a new classroom, teacher or year group. This time can be especially difficult and may well require extra planning and support. Schools can do this in many ways.

- Extra visits
- Talk lots about what’s going to happen
- Photos of new school and staff – six weeks can be a long time out of school/routine to get anxious
- Virtual tours
- Video from school or pupil introducing themselves
- TA leaflets to give staff at new school/class
- Recommend TA training to the feeder school

### What should SEN support look like in school?

Children don’t need a diagnosis to receive support at school and neither do they need to be on the SEN (Special Educational Needs) register to gain support. As long as the school recognises that the child needs extra support in school then they may decide to put the child on the register or on a monitoring list. If your child is on the SEN register, the school will receive a small amount of funding that will go towards supporting your child so make sure they are having access to some support if this is the case as schools do have a legal obligation to make reasonable adjustments to meet a child’s needs.

Support in school may look very different for different children according to their needs. This could be extra TA (teaching assistant) support or any extra interventions put in place to support and enhance their learning.

Please refer to the possible strategies above to see more specifically what type of support a child with TS could expect in school.

Schools should assess each pupil’s current skills and levels of attainment on entry and regular further assessments should take place. These should seek to identify pupils making less than expected progress. The SEN Code of practice refers to four broad areas of need:

- Communication and interaction
- Cognition and learning
- Social, emotional and mental health
- Sensory and/or physical needs

The school should use a graduated approach following the cycle of assess, plan, do and review:

### Assess, plan, do, review

**ASSESS – Identify what the problems are:** Attainment (tests), behaviour (observations), Screening assessments (Nessy, Connors etc.), external support (CDC, CAMHS, S&L, OT), parents and pupils views.

**PLAN –** Teachers and SENCO’s meet termly (separate and in addition to parents evening) with staff to agree in consultation with parents about adjustments, strategies, interventions and support with a clear date for review.

**DO –** Class teacher and SENCO work together in effective implementation of support day to day for pupils.

**REVIEW –** effectiveness of support and interventions should be reviewed regularly (agreed date) and revised. The parents should be involved in this at least termly in addition to the usual parent evenings.

**ILP/IEP –** a record of these outcomes, action and support should be given to all staff and parents to make sure plans are happening. (COP – 2015)

If, after a certain amount of these plan, do and review cycles the pupil is still not making expected progress, the school should consider requesting an Education, Health and Care needs assessment. It is important to know that the parents can also apply for this too. However, it is best to collaborate with school on this if possible as they will be the ones having to submit most of the evidence towards this.

### What is an EHCP?

An Education Health Care (EHC) plan is the document which replaces the old system of Statements of SEN and Learning Difficulties Assessments for children and young people with special educational needs.

An EHC plan is a legal document that describes a child or young person’s special educational, health and social care needs. It explains the extra help that will be given to meet those needs and how that help will support the child or young person to achieve what they want to in their life. They are intended for children and young people from birth and up to the age of 25 who need more support than what the school/setting can provide from the SEN Support resources.

It consists of **outcomes** and identifies the **provisions** needed to meet those outcomes from a number of professionals involved in the child’s care.

Most children with TS won’t need an EHC plan. An EHCP will only be considered if:

- A child is not meeting expected progress
- A school feels they can’t meet the needs of the child within their SEN support of 20+ hours
- A certain number of access, plan, do and review cycles have been done and a school feels they have done everything they can within its remit

An EHC plan can only be issued after a child or young person has gone through the process of EHC needs assessment. At the end of that process, the Local Authority has to make a decision, either to issue an EHC Plan or not. You can find out more about EHCP’s on [www.gov.uk/children-with-special-educational-needs/extra-SEN-help](http://www.gov.uk/children-with-special-educational-needs/extra-SEN-help) and [www.westminsteriass.co.uk/pages/information-and-advice/education/ehc-plans/ehc-timeline](http://www.westminsteriass.co.uk/pages/information-and-advice/education/ehc-plans/ehc-timeline) and [www.ipsea.org.uk/ehc-needs-assessments](http://www.ipsea.org.uk/ehc-needs-assessments).

### Support in exams

Some children with TS will not need any SEN support at all but it’s important if they do that we explore all possibilities as early as possible to make sure they have full access to the curriculum. When it comes to a child’s GCSE exams the exam board will only grant extra support if a school can show it is the child’s ‘usual way of working’ which is why it’s so important any support for your child is established as early as possible.

There are many ways in which a child can receive support with exams at school depending on their needs. For example, 25% extra time for all assessments, SATS, GCSE’s or A Levels, different/quiet room, stop the clock, extra breaks, scribe/reader. This support will have to be decided by the SENCO and access arrangements will be applied for to the JCQ (Joint Council for Qualifications). You can find out more about whether your child would be considered for access arrangements on [www.jcq.org.uk/exams-office](http://www.jcq.org.uk/exams-office).

### Questions to ask yourself

- Is the school meeting the needs of my child? – SEN Code of Practice 2015 – ‘best endeavours’. [www.gov.uk/government/publications/send-code-of-practice-0-to-25](http://www.gov.uk/government/publications/send-code-of-practice-0-to-25)
- Is the school doing everything they can to remove any barriers to learning for my child?
- Are the school providing ‘reasonable adjustments’ to cater for my child? – Equality Act 2010 – schools duty. [www.legislation.gov.uk/ukpga/2010/15/contents](http://www.legislation.gov.uk/ukpga/2010/15/contents)
- Can I be sure the school are not setting my child up to fail?
- Has my child got full access to the curriculum?
- Is my child reaching their full potential?
- Is my child happy to be at school? If not in school, why?

### In summary

- Tics are not intentional attempts at gaining attention or to be disruptive.
- Tics are not the student’s fault (or the fault of parents).
- Tics should not be taken personally.
- Children should not be punished for their tics.
- Tics are not simple habits that can easily be replaced or stopped.
- There is no one-size-fits-all “cure” for tics.

### Frequently asked questions

#### *Should my child be forced to go to assembly?*

Assemblies can be a very anxiety driven time for a child with TS. That expectation of being silent and sitting still in a large room full of children and staff who may question the child as to the noises and movements they may be making. We have to question if a child finds it difficult to sit quietly and still in assembly then is it important that they go at all? If it is a time of high anxiety then maybe if they are happy to do so, there could be another intervention they could do instead at this time? It is important to build up these children's resilience but it's also important to pick your battles and consider if certain situations are really necessary? Consider if this situation is just setting this child up to fail? It's also

important to consider a child with TS that actually really wants to go to assembly just like their peers and wants to be part of the school community. In such cases we need to look into ways of supporting the child in this decision and making it as much of a comfortable experience as possible. Consider seating the chair at the back or end of aisle so they can easily exit if they feel they need to go and release some tics. Consider the use of quiet fidget toys to help distract the child from their tics and aid concentration.

#### *Is this the right school/setting for this child?*

If you have exhausted all other possibilities, then this may be something to consider as a last resort.

### Case studies

#### CASE STUDY ONE

Gender: female

Age: 14

Setting: mainstream high school

#### *Background/school issue*

Sarah was having trouble with her TS at school as one of her tics was to draw all over the work. She also had OCD. Her OCD was making her touch and pull the hair of the person sitting next to her which resulted in her being constantly misunderstood by both teachers and peers. She was constantly being teased by her friends and became very isolated and frequently missed school because of her anxiety of coming to school and facing this upset each and every day. Her teachers thought that she was being unkind even though she told them she couldn't help it and she was being punished in line with the schools behaviour policy with detentions and isolation. In turn these punishments were crushing her mental health as she knew inside she was being punished for something she couldn't help. Her parents were thinking about home schooling as she was so unhappy at school.

#### *Provision/strategies*

Firstly, we encouraged the school to get some training so that they could fully understand TS and the possible barriers it can bring to learning for children with TS. The school fully embraced the training and all staff attended a session and felt they were confident enough to put some strategies in place for Sarah to help her have full access to the curriculum. They quickly replaced any paper work from sheets or books with a laptop for

Sarah to do all her work on which took away the urge for her to scribble all over it. They then focused on some 'pupil voice' sessions to talk with Sarah and give her the chance to explain her TS and what her tics were and how the teachers and children could help her. The SENCO worked with Sarah to make a 'pupil passport' which was given to all teachers so that they could fully understand Sarah's needs and support her where necessary. They did a whole school assembly for the children and explained TS and how they were going to make things easier for Sarah by understanding TS. Sarah asked to move to a place in her class where she wasn't sitting with people that had long hair so she could remove the temptation of wanting to pull hair and asked to sit by the door so that if she became overwhelmed by her tics she could exit the room for a break without having to bring attention to herself or make a fuss to anyone around her. Each time a teacher thought she was misbehaving they would simply ask her if it was a tic and she was able to vocalise what was going on.

#### *Outcome*

Sarah was able to be fully understood by all staff and pupils, continue to stay at school and learn with her peers. She was no longer punished for her tics, grew in confidence to talk about her TS and fully embrace her differences. Sarah was happy and started to love school again and no longer feared attending. She now has a really strong group of friends and her mental health has considerably improved. She now feels she is able to get on with her learning and reach her full potential and is in fact top of the class.

### CASE STUDY TWO

Gender: male

Age: 11

Setting: mainstream high school

#### *Background/school issue*

Jack had TS since he was 6 and was also diagnosed with ADHD. He always struggled at school to access any learning but after starting high school he struggled even more and was falling further behind in his work. Jack was constantly being told off by teachers for not listening, lack of quantity of work being produced, not sitting still, rocking in his chair and constantly eating his pens. He was always described by his teachers as an angry boy and always came to school unprepared without PE kit, calculator or books etc. He was punished by teachers constantly for forgetting his homework, for acting the class clown and distracting others. His parents found it very hard to get him to focus and do any homework at home and home life was generally hard work for all members. Jack did have both motor and vocal tics but they didn't seem to be getting in the way of his learning specifically. After talking to his teachers over the phone it quickly became clear that Jack had some obvious executive functioning difficulties. We explained to the SENCO that children with TS can often have trouble with their executive functioning skills meaning that the following things may be very difficult for Jack. Paying attention and focusing, organising and planning, starting and completing tasks and shifting focus from one task to another.

#### *Provision/strategies*

We provided Jack's school with some training. We explained that in order to best support Jack with his executive functioning difficulties the best things to do were to model good organisational skills, give him time to process, teach Jack to pause and reflect before responding, use writing frameworks/task planners to support his work outcome and keep all expectations on work and behaviour clear and consistent. After the training the school also realised that Jack was a boy that needed to have access to frequent movement breaks and best accessed work in short snippets with lots of encouragement. We put in place a 'time out card' for Jack that he could use when he found learning a bit tricky. This enabled him to be able to ask permission to remove himself from class to have a walk down the corridor and move around for five minutes and release some tics before returning to his lesson and continue with his work. We recommended Jack sat at the front

of the class where he could be re-focused by his teacher each time he felt distracted. We helped school understand that due to Jack's tics he may not be able to listen easily and may possibly miss the lesson input and not know what is expected from him. To help him in this we suggested Jack have another separate input from the teacher once the class were set off working independently and help Jack get started with his work. We put in place a reward chart for Jack which he loved and enabled him to be encouraged to try his best and keep on task. To help Jack with his organisational skills we put in place that he would come into school five minutes earlier each day to be met by a member of the pastoral team. This would help Jack get settled for the day, go through his timetable and make sure he had everything he needed for the day ahead thus avoiding unnecessary punishments.

We recommended the parents purchase a piece of jewellery to prevent Jack eating school pens as he still needed the sensory feeling of chewing in order to help him to concentrate. We put Jack's family in touch with our Support Manager to get access to local support groups and meet other families with children with TS and the family were able to attend one of our TICfest breaks. We talked to school and they allowed the parents to differentiate Jack's homework to make it more manageable at home by reducing the expectation on quantity but still having the expectation of the quality of work needed.

#### *Outcome*

Jack no longer felt frustrated and angry at school. For the first time in his life he felt understood, supported and work was made much more accessible to him. He started to clearly understand what teachers expected from him and no longer felt the need to act like the class clown as he felt able to let his tics out without feeling judged. He finally felt able to succeed at school and achieve goals that were set feeling that what was being asked of him was manageable. He was very proud that he was receiving less punishments. His parents were happier at home as pressure was relieved from school work and they felt more understood as a whole family by having access to meeting other families. Jack made some new friends at TICfest who he continued to keep in touch with and now felt part of a community of people that were the same as him and people he could talk to about his TS.

### CASE STUDY THREE

Gender: male

Age: 9

Setting: a small mainstream primary

#### *Background/school issue*

Nathan was diagnosed with TS at the age of 6 which presented with mild vocal and motor tics at first but when he moved to year five he suddenly developed Coprolalia and the school were shocked that he started swearing. The school made the decision to send him home and were concerned that they would be unable to meet his needs at school. The school were worried about the safeguarding of the other students. Nathan was a capable boy academically and was on target with all of his learning. Nathan was upset he couldn't come to school but also unsure of how he would manage each day without upsetting anyone. The school were worried that he had upset many staff members and pupils with his insults. School were unsure if the swearing was actually a tic or not as they noticed they were usually said in context. The school were desperate for advice on how they would be able to have him back at school. The family were very traumatised by comments from other parents and they were concerned that they had got the total wrong impression about their son. He felt quite isolated and was never invited on play dates or parties with friends.

#### *Provision/strategies*

Firstly, we provided the school with our training. They were relieved to know that there were things we could do to help keep Nathan at school. Training made a massive difference here as they quickly realised that Nathan's swearing was totally involuntary even in situations that may seem in context. All staff and pupils (via a structured assembly) received awareness training and teachers approached Nathan to let him know they understood and were willing to do all they could to support him. The pupils were very supportive too and the school made sure that there was a member of the pastoral team available at any time for the children to

go to if they felt saddened by any tics Nathan had come out with. We suggested that the school sent home a letter to all parents across the whole school (with the family's permission) informing them about Nathan, the difficulties he had and how the whole school could support him. We also put in place an information event where all parents were invited to come and learn about TS, give them the opportunity for further understanding, a chance to air any concerns and ask questions. We suggested Nathan was supported by a teaching assistant at all times so that they could intervene at times where Nathan felt most anxious and tics may be at their most severe. They decided that the busiest times of the day (transition from lessons, break times, start and end of school, etc.) were his most vulnerable and most ticcy times so the TA started to walk with him at these times and distract him by talking and focusing on different things to divert his attention. We advised a lot of pupil voice work to help Nathan feel listened to and supported. Lastly, we advised with Nathan's permission that he may feel more comfortable playing in the smaller playground surrounded in a smaller group of friends rather than being exposed to a larger group of children that didn't know him well.

#### *Outcome*

With our guidance the school were able to successfully have Nathan back in school full time and meet all his needs with a few reasonable adjustments as suggested above. He now has been allowed back to school full time and the teachers are confident that they can meet his needs. Nathan's mental health has improved and he now feels confident to go into school and learn and be with his friends. He now has an open relationship with all teachers and students and feels able to speak to them about his worries of upsetting them unintentionally. He now has more friends and started getting invites to his friend's houses. And the parents found that other parents approached them to show their support. Nathan now feels accepted and a proper member of his school community.

## Useful organisations

### The Independent Parental Special Education Advice (IPSEA)

A national charity providing free legally based, independent advice and support to families who have children with special educational needs.

How they can help: Problems with schools, requesting statutory assessment, proposed statements, annual reviews, disability discrimination, exclusion, etc.

[www.ipsea.org.uk](http://www.ipsea.org.uk)  
[www.ipsea.org.uk/what-you-need-to-know/ehc-plans](http://www.ipsea.org.uk/what-you-need-to-know/ehc-plans)

### ACE Education Advice

A charity offering a comprehensive range of advice and information on education issues. Their information is based on current education law and guidance and covers state funded education for children aged 5–16 years in England only.

How they can help: offer support and advice on special education needs, anti-bullying, exclusion.

[www.ace-ed.org.uk](http://www.ace-ed.org.uk)

### Information, Advice and Support Services Network (IASSN)

Provide training to local information Advice and Support services (IAS) across the UK. IAS Services have a duty to provide information, advice and support to disabled children and young people and, those with SEN and their parents. There should be an IAS Service in every local authority.

[cyp.iassnetwork.org.uk](http://cyp.iassnetwork.org.uk)

### SOS!SEN

The independent helpline for special educational needs. They offer a free, friendly, independent and confidential telephone helpline for parents and others looking for information and advice on Special Educational Needs (SEN).  
How they can help: specialise in helping people to find their way through the legal and procedural maze which is so daunting to so many who try to obtain satisfactory provision for a child's special needs.

[www.sossen.org.uk](http://www.sossen.org.uk)

### Home Education UK

Provides information, resources and support to people home educating or considering home educating in the UK. Home Education UK special hosts the HE-Special-UK mailing list: a group of families who home educate children with special educational needs.

[www.home-education.org.uk](http://www.home-education.org.uk)

### GOV UK

Contains useful advice on parent's rights and obligations with regards to home education.

[www.gov.uk](http://www.gov.uk)

### The Home Education Advisory Service

A UK home education charity dedicated to the provision of advice and practical support for families who wish to educate their children at home.

[www.heas.org.uk](http://www.heas.org.uk)

### The Children and Families Act 2014

[www.legislation.gov.uk/ukpga/2014/6/part/3/enacted/Children and families act 2014](http://www.legislation.gov.uk/ukpga/2014/6/part/3/enacted/Children%20and%20families%20act%202014)

## TOURETTES ACTION SCHOOL RESOURCES

Tourettes Action (TA) has a range of resources for families and teachers with advice on supporting children with TS in school:

- [TS social story](#) – a learning tool to support the exchange of information
- [TS passport](#) support aid
- [Key facts for teachers](#) leaflet
- [What makes us tic](#) leaflet
- [Transition back to school](#) by Education Manager Lucy Toghill
- [What is TS?](#) – a presentation for young people presentation
- [Online training for school staff](#) presentation
- [Tic Talk – Anxiety, school and TS](#) – a video by specialist teacher Katie Skinner
- [Guidance for people with TS going to university](#) factsheet
- [Post-16 education options for people with TS](#) factsheet
- [How tics can affect learning](#) – a video by Harvey Redman
- [Anxiety and TS](#) factsheet
- [Sleep problems and TS](#) factsheet
- [Behaviour and TS](#) factsheet
- [Anger and TS](#) factsheet

You can find all this and more on our [education](#) page on our website.

TA can also arrange to speak to schools to help explain TS and offer support for children with TS. If you are a parent or teacher of a school who is struggling to understand and support a child with TS, TA can provide telephone and face to face advocacy support in England, Wales and Northern Ireland.

We also offer bespoke advice for parents regarding any questions or concerns about their child’s education and school experience.

Please contact our our Education Manager Lucy Toghill to speak to us about this service by emailing [lucy@tourettes-action.org.uk](mailto:lucy@tourettes-action.org.uk).

TA also has factsheets with advice for young people with TS in higher and further education. You can download them from the website [www.tourettes-action.org.uk](http://www.tourettes-action.org.uk).

## WHO TO CONTACT FOR FURTHER SUPPORT



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**Education Manager**  
07394 559 025  
[lucy@tourettes-action.org.uk](mailto:lucy@tourettes-action.org.uk)



