

Understanding Tourette Syndrome (TS) In an Educational Setting

School/College Staff Training

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Welcome to the Tourettes Action school/college staff online training.

The aim of this training is to:

- Increase Tourettes awareness for all staff in an Educational setting.
- Bring awareness to the barriers to learning children with TS may face in school.
- Provide your setting with tried and tested strategies they can easily put in place to best support children with TS.

Which of these statements are True/False?

- A child shouldn't have to apologise for a tic.
- A TS child is more likely to have TS and one other co-occurring condition.
- A child can develop TS at any age.
- Tourette Syndrome is a lifelong condition.
- Tourette Syndrome is a Mental Health condition.
- Parents of a TS child will be likely to have TS too.
- It's easy to get referred for a diagnosis of TS.
- The GP can diagnose TS.
- Children with TS have a below average IQ.
- Children with TS best learn in quiet learning environments.
- A child with TS is more than likely to suffer with anxiety.
- Children with Tourette Syndrome use obscene language as part of their condition.
- Children with TS have behaviour issues.
- Children with TS will lead a normal life. E.g. drive a car, get a job, get married.
- A child with TS can control their tics.



Discussion point:

At this point please fill in the 'What do you know about Tourette Syndrome?' sheet.

Fill out what you can and if there are any you are unsure of then we hope you will have the answers by the end of the workshop.

What do you know about Tourette Syndrome (TS)?

What is your perception of TS from the media?

Have you ever known/worked with anyone with TS or Tics?

What symptoms did they show?



Unfortunately a lot of what we know about TS is what we have been shown by the media but in fact, in reality, TS presents very differently.

It's always useful before starting this training to think of someone you are working with or have worked with in the past that has/might have TS or another tic condition.

What is TS?

- Tourette Syndrome is a condition that causes involuntary tic. Tics are sudden movements and sounds that cannot be controlled.
- Tourette Syndrome (TS) is a genetically determined neurological condition.
- Tics typically start around the age of 6/7 years and tend to peak around early adolescence.
- TS affects one school child in every hundred (as common as autism) and is more common amongst boys (75% are boys).
- TS can be initially triggered by emotional events
- Tics (involuntary sounds and movements) present for at least 12 months



Although genetically determined, it does not necessarily mean to say Mum or Dad will have TS. It could be that through a clinician discussing the family history, they find a relative that may have had symptoms in the past but left undiagnosed or that they suffer with one or more of the co-occurring conditions. This family history will be key for the diagnosis criteria.

Co-occurring conditions will be discussed in more detail later.

Hormones can play a big part in TS. At around the age of 6 or 7 children's hormones start to change 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.

Emotional events have been reported in some cases to trigger tics. These could be things such as a change in circumstances at home, a loss of a loved one, a medical trauma etc.

- Changeable/wax and wane
- Not just vocal and motor tics – visual, intrusive thoughts, conversational tics
- Increased by stress, anxiety, excitement, hunger, tiredness, sensory changes
- Decreased by exercise, distraction, deep concentration
- In approximately 50% of cases tics can lessen by adult hood (Neurodevelopmental)
- 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.

Many students 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.

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 in are all examples that you may notice could be a reason for an increase in tics.

https://www.youtube.com/watch?v=_AqLU2JZvVk

This link is to a video that shows the common misconceptions people sometimes have about Tourette Syndrome.



This video was made by Tourettes Action to help dispel any myths and squash any stigmas around this condition.

It was made in the style of the BBC series on 'What not to say'.

Destroying the myths about TS

TS is often misunderstood as a condition which makes people swear, or say 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, between 15 – 20%.



Coprolalia is not very common but in fact something we are contacted a lot about from schools given the very nature of safeguarding and possibly the most difficult tic to manage in school.

What is Coprolalia? (The Coprophenomena)

Possibly the most tricky type of tic to manage in a school setting.


- Coprolalia is an involuntary, uncontrollable outburst of obscene or socially inappropriate derogatory remarks. These can be verbal utterance of obscenities (Swear words), sexual words and connotations or religious and racial slurs. This also includes 'mental coprolalia' which describes repeated thinking of obscenities and profanities.
- Coprographia: the compulsion to write down obscenities and profanities
- Copropraxia: the uncontrollable performance of obscene gestures



- Palilalia – repetition of the person's own words or phrases
- Palipraxia - repetition of the person's own movements
- Echolalia – involuntary repetition/imitation of another person's spoken words
- Echopraxia – involuntary repetition/imitation of another person's movements



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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:

Transient tic disorder (Provisional) – vocal **OR** motor tics that tend to be transitory. Tics only last a few weeks or months.

Persistent tic disorder (Chronic) – vocal **OR** motor tics that tend to persist rather than be transitory. Tics occur for more than 1 year.

A tic disorder (not specified) - tics are present, but do not meet the criteria for any specific tic disorder.

Sudden Onset or Functional Tic Disorder – [Specific Strategies](#)



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Tourettes is a spectrum condition. To be classified as having TS there must be both vocal and motor tics present for over a year.

Since the Pandemic hit in 2020 there have been a remarked increase in pupils experiencing a sudden onset of tics and due to the very nature of their severity these can be very difficult to manage in a school setting. This has also been reported to have been effecting multiple students within the same schools. There may be reasons for this that will need to have been checked with a clinician and it may well be that these are different tics typically experienced by someone with a diagnosis of TS. Whatever the reason or diagnosis of their tics, the strategies will generally be the same for the management of these at school. The only difference may be the medical treatment offered to alleviate the tics.


However, please click on the link above if you want to find out more specific information on strategies specific to sudden onset tics.

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Here are some examples of common motor and vocal tics:


	Motor Tics	Vocal Tics
Simple	<ul style="list-style-type: none"> Eye blinking Eye rolling Grimacing (pulling faces) Shoulder shrugging Limb and head jerking/head nodding Abdominal tensing 	<ul style="list-style-type: none"> Whistling Throat clearing Sniffing Coughing Tongue clicking Grunting Animal sounds
Complex	<ul style="list-style-type: none"> Jumping Twirling Touching objects and other people Obscene movements or gestures (copropraxia) Repeating other people's gestures (echopraxia) 	<ul style="list-style-type: none"> Non obscene socially inappropriate (NOSI) behaviour (e.g. remarking about a person's weight or inappropriately touching someone). Involuntary swearing (coprolalia). Repeating a sound, word or phrase (echolalia).



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Here is a list of tics that you may have seen in pupils either with TS or undiagnosed.

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Hidden Tics

- Visual tics e.g. looking at shadows/counting objects.
- Intrusive thoughts e.g. harming someone or themselves.
- Suggestive tics e.g. overwhelming urges to follow through inappropriate suggestions.
- Thought tics e.g. something we all think but kids with TS can't regulate. (It can be a bit like having a window into their soul).
- Conversational/contextual e.g. these can sound and appear to be in the correct context but they just find it very hard to switch off their regulator button.
- Sometimes these tics can be completely random and not something a student is thinking about at all.



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It's really important 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 students may be dealing with internally that you may not be aware of. These can often be the ones that are most uncomfortable for them. Here are just a few common ones that we have found students struggling with in schools and colleges. There may be many more so it's important to discuss these with the student.

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

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

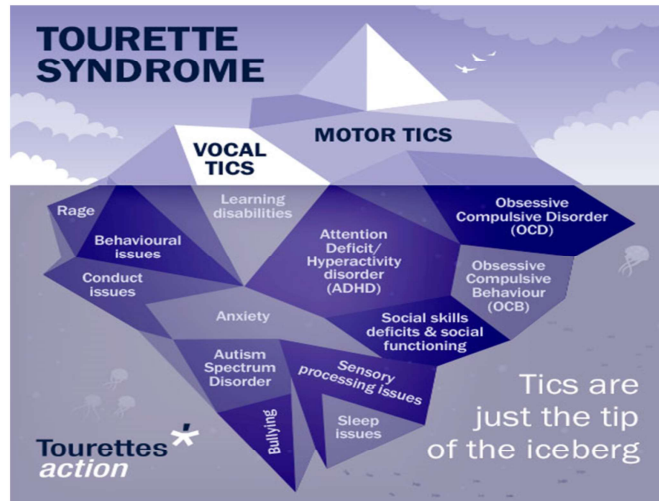
An example of a conversational/contextual tic could be, for example, if when telling a student to concentrate, they utter the words 'shut up'. If the teacher does not know the student well then this could appear like a genuine response and not a tic. However, please consider the fact that the student 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.

Co-occurring Conditions

- 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)
- For many, the co-occurring conditions can be more challenging than the tics.



We rarely see a student with just pure TS. This is really important to know as it may not be a student's tics that are causing them their main issues in school.



There is much more to TS than you see on the surface. There is often lots more going on than you realise.



When we look at this there is no wonder that so many students with TS suffer from rage or in general with their mental health. To have so much going on can be very confusing for the student so us teachers need to be very understanding of all the issues these children may be facing.

Why might getting a diagnosis be important?

- Correct labels/diagnosis
- School support (i.e. better understanding, reasonable adjustments, EHCP)
- Treatment options
- Permission to parent differently! Grieving process.



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.

I like to use the analogy of a cake for this. A cake is very similar to a child. 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.

After Diagnosis

- Access to CDC / CAMHS services
- Grants / Possible statutory support, i.e. DLA/PIP
- Local support groups/befrienders
- Leisure discount cards
- Psychoeducation for the children, family and school (learning as much as we can about TS)
- Therapies – HRT (Competing response), ERP (Build up of suppression over periods of time) , CBITS (Comprehensive Behaviour Intervention for Tics)
- Medication

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If a child is lucky enough to even get a referral to CAMHS and gain a diagnosis this could open doors for them to gain better understanding and support.

Local support groups are very important for both the child and their family members. It may be a chance for them to meet other families and realise they are not on their own. Please refer parents our way if you feel they would benefit from this as we may be able to help.

Its important to know that some parents may go through a grieving process as they may 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 support they can eventually learn and give themselves permission to parent differently.

Psychoeducation is very important for the child. By this, we mean its important they know what TS is, how it effects 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 we have to respect that. However, from experience, this is not a very helpful situation to be in. In these cases 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.

Education creates knowledge and a greater understanding. Evidence suggests that

children do much better at school if they feel supported, understood and accepted in their own school community.

Therapy and medication are not for everyone. It's important to know that these are treatment options that parents and the children themselves can choose to have access to. Please do not experiment with these therapies at school. These have to be carefully considered by the parents and delivered by trained therapists.

Mental Health

- Tourette Syndrome is not a mental health condition but it can certainly effect a student's mental health.
- Anxiety, rages, depression and suicidal thoughts. Such symptoms can be made worse by factors like hormones, bullying and change.
- A huge amount of stigma surrounds TS, often limiting the confidence and self-esteem of those diagnosed, especially young people.
- Encourage a student 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.



TS is not a mental Health condition but it can certainly effect a persons mental health.

If a student does suffer with anxiety, rage, depression, bullying, rise in hormones, etc. its no wonder they may be suffering from poor mental health as this is a lot to go through.

Education and awareness is the key!!!!

Negative cycle



Sometimes tics can fall into a negative cycle and its important to work out where best to break this cycle in order to support the student.

Where do you think the best place would be to break this cycle and intervene?

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 student that make them anxious and make adjustments to their environment where possible, in order to break this cycle.

In order to do this we must involve the student in some **PUPIL VOICE** sessions. Talk to the student. Discuss together what their tics are, what makes them worse and how you could help them.

Case study example

Nathan was a high achieving boy with TS and his teachers thought he hated maths and disliked the class teacher. Every time he went to maths he started ticcing very badly. He used to frequently get sent out of maths due to the disruption this caused. After a pupil voice session he was able to visit the class empty with the SENCO and look at his learning environment in maths. It turns out that Nathan disliked the chair he was sitting on as it scratched against his school jumper causing him great sensory pain, distraction, discomfort and anxiety. The SENCO changed his chair to one of his choice and his tics significantly reduced in that lesson from then on.

It's always this simple but things are not always as they seem.

Tics vs Neuro-typical Bad Behaviour – The magical question!

- Tics can sometimes appear to be in context. You may need to ask the student.
- Bad behaviour alongside TS can be a sign of the child trying to regain some control and distracting from their tics.
- Get to know the student rather than challenging and questioning them and listen to your instincts.
- Talk after/ask student ...What happened? Why do you think that happened? How can we help you next time?
- If you're unsure then assume it's a tic.
- Never punish a student for a tic.



This is the main question that gets asked by teachers and support staff!

Students with tics can be misunderstood and sometimes come across as being badly behaved so it's up to us to find out why they are displaying such behaviours.

Consider this. Some students with TS have told us that at times it's much easier 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 (in their own words as) 'weird' or strange.

We understand that it can be impossible at times to unpick if a tic is genuine or not but we would advise to get to know the Student rather than challenging and questioning them all the time. Then after having this training and building a relationship with the student, we would then hope that you would become confident enough to make that call.

It's important to know that we don't expect a student to apologise for having TS but we must certainly encourage them to apologise if their tics have upset or hurt anyone physically or verbally. 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 Sanction/Management strategy?

- Sending a student out of a lesson?
- Staying behind to finish work/take work home?
- Missing play/PE?
- Detentions?
- Isolations? Suspensions/expulsions?
- Sanctions may need to be differentiated. What is this teaching the student?
- Behaviour policies may need to be adjusted.
- **Negative Behaviour is a form of communication. There is always a reason for 'bad' behaviour.**



So after being clear that a student must not be punished for a tic, it is possible of course that students with tics may also experience some negative behaviours much like their neuro-typical peers.

Consider the above common sanctions delivered by many schools. Think about the impact these sanctions will have on the student in question.

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 sanctions too and behaviour policies may have to be adapted here as well.

Schools pride themselves that all students are treated the same which in some ways is great but we must remember that all students aren't the same and it may not be appropriate to always be treated the same as their peers in terms of sanctions. For example, putting a child with mental health concerns in isolation can be even more detrimental to their mental health.

Of course students with TS can also misbehave much like their peers and it is important that attention is brought to this and dealt with appropriately but this may need to be dealt slightly differently to their peers.

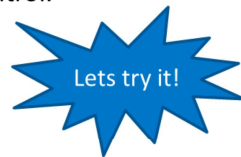
Some SEN students can feel a big sense of injustice at times of negativity so it's very important that we give them time to reflect and talk to them as they may not even

realise where they went wrong and why they are being told off. They may need more explanations than their peers.

Make sure you 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.

Can tics be controlled?

- Although tics are completely involuntary, some people are able to suppress their tics for a short time. However, this can be very difficult.
- A helpful way of understanding this is to compare it to a blink, cough, yawn, sneeze or scratch. For a short period of time it is possible to keep your eyes wide open and avoid blinking but eventually you will have to blink as the urge is too strong to control.



- Premonitory urge – the feeling some people get before a tic is released.



Tics can be extremely difficult to suppress and not let out. If we expect students to suppress their tics then this could be extremely uncomfortable and could have repercussions later.

Lets try it!

It can be extremely painful and uncomfortable to suppress a tic as this exercise will illustrate. Try not blinking and keep your eyes open for a whole minute. How easy was it? How did it make you feel? This is similar to the feeling many people with TS report they get when they have to hold their tics in. Imagine trying to do that all day. Not only would they be dry and painful, you wouldn't be able to think about anything else apart from your eyes.

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 may be used and worked on if a person decides to try some CBT therapies. It's important to stress that this may only be a few seconds warning and some students do not get a premonitory urge at all.

- Some people will be able to suppress their tics more easily than others and some just may not want/be able to as find it to uncomfortable.
- Takes a lot of energy to suppress – tiredness is real!
- It can be quite common for students with TS to suppress their tics at school or college, yet families will notice a marked increase in their child's tics at home. (Suppression v's environmental changes)
- School is very structured with reinforcers that may make a student want to control their tics. In comparison, home life is more relaxed and therefore helps children to feel at ease with expressing their tics.
- It can take a great measure of concentration to resist the urge to tic. If a student is ticcing **or** suppressing a tic they may find concentrating very hard.



It's very important to know that whilst a student is ticcing or suppressing, they may not be able to concentrate. Any work or input that is done during them ticcing or suppressing may need to be reinforced after again on a one to one basis. These students may also be the ones that have not yet started a task or been able to complete or achieve the learning objective.

You may have heard a parent say 'my child tics loads at home', and yet at school you may not see many tics at all? Home is a safe, non judgemental place where children can let out their tics, so even if as a school, you don't have any 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 students if they feel comfortable enough to tic at school.

How can TS create a barrier to learning?



TS does not in itself affect IQ, but it can have an effect on a student's ability to learn. For example:

- concentrating on a lesson can be hard if a student 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 students tired which can effect their work.
- Feeling socially isolated from peers can also 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.
- Vocal tics may make a student reluctant to read aloud, ask or answer questions and even sometimes to ask for help.
- Both motor and vocal tics can be physically and mentally exhausting and sometimes painful for the student experiencing them, leading to tiredness and lack of enthusiasm. Look out for signs of disengagement.



Bear in mind that some students with TS may have OCD or just rely heavily on routine to cope with their difficulties. If a student takes a while at night to wind down and calm their body from ticcing etc. then this could take a long time. Some student's sleep may be disturbed as some can even tic in their sleep.

Medications

There are medications available for people that suffer with severe TS but its worth noting that they can come with side effects. Medication is usually a parents last resort after trying other therapies/strategies and for some 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. Medication can also make a child sleepy. So bear in mind that this could have a huge impact on their learning as they may find it incredibly difficult to concentrate in class.

A student may have difficulty on the playground with friends and come into class after break time upset and extremely ticcy and unable to get started on their work and if this involves another child in the class then this could impact on the whole class and the entire next lesson.

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'.

Some children may come across as tired, unenthusiastic or even disengaged in their learning, so consider the fact this may be due to TS related factors.

Homework!!!!!!!!!!!!!!



Have realistic expectations.

Reduce the **amount** but not necessarily **difficulty**.

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Homework can be a big issue for students with TS. What we advise is that you either differentiate the homework or if a student doesn't want to appear different from their friends, then talk to the parents and allow them to differentiate the homework at home. Encourage them 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 for example, then encourage them to try the first few. Tiredness is real for these students and sometimes they are just not in the right frame of mind to be able to manage more school work at home after a full day at school.

Executive Functioning Skills



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



Organization 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 your 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.

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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.

Executive Functioning

Executive Functioning is a set of mental skills that include 3 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 everyday to learn, work and manage everyday life. Difficulties with Executive functioning can make it hard to focus, follow instructions, regulate emotions etc.



Executive Functioning

How does this effect our students? What can this look like in school/college?

Difficulties with the following:

- Paying attention and focussing
- Organising and planning
- Starting and completing tasks
- Shifting focus from one task to another
- Retaining facts
- Following instructions
- Impulsivity



Executive Functioning

How can we help improve student's Executive Functioning?

- Modelling good organisational skills
- 5 minute earlier start time
- Give them time to process
- Teach to pause and reflect before responding
- Use writing frameworks/task planners
- Keep expectations clear and consistent
- [Executive Functioning - Specific Classroom Strategies](#)



If a student gets overwhelmed by the busy times of the day for example the start, then maybe providing a member of staff to be able to meet the student 5 minutes earlier to enable them to miss that chaos, go through their timetable and making sure they have their pe kit, maths equipment, homework etc. and are ready for the day so that we are not setting them up to fail before they have even begun. If we know these are things they struggle with then lets give them strategies and support them rather than punishing them when things do go wrong.

Click in the link to find more specific classroom strategies for children that suffer with poor executive functioning. This factsheet was written by one of our associate Educational Psychologists who specialises in TS.

Clear expectations and consistency is the key!!!!

How can you help? Suggested strategies

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Here are a few things we have implemented in schools that have proved successful in supporting students with TS.

Please remember that all students are different and that not all of these strategies will work with all students with TS.

These strategies will not be difficult to implement and may already be things you have already tried out with other SEN pupils in school but they are worth considering for students with TS too.

General Strategies/Good Practice

- Ignore the episodes during them so the tics don't get attention
- Distract them if they start to panic/show lots of tics - for example, ask them to deliver something to another classroom
- Reduce the audience and ask others to carry on normal activities
- Educate others around about the need to NOT give attention to the tics
- Try not to respond to tics, unless they really require a response e.g. danger/safeguarding of other pupils.
- Normalise the tics
- Discuss possible triggers for the tics



Advice from our clinicians suggests that the less attention we give to the tics, the less a child may tic. The brain is very clever and learns from both negative and positive attention so we have to be mindful on what exact attention we are giving.

Students in the main are very accepting and you should find that given the chance to learn more about TS, they will be more understanding. We can only ask people around us to ignore tics if we educate them and spread awareness. TS can be a very antisocial condition and one that is very hard to hide. By explaining, we are able to normalise what is happening to the students.

- Consider/investigate modifications to the environment to prevent potential triggers, e.g. sensory walk
- Lots of praise and attention for managing the planning of the situation/triggers to the tics but **not** the lack of tics themselves
- Have a plan in place to automatically revert to with the least fuss possible
- Avoid sending home and only use this as a last resort to aid safety or suffering exhaustion.
- Approach the student and family to find out how their TS affects them and keep communication as open as possible.
- Build a relationship with the student so they feel understood and safe.
- Consider placement of more than one pupil with tics in the same class.



Environmental factor can be huge for a student with TS. Many students with TS are reported to have sensory issues which may play a part in the levels of anxiety that they experience, which in turn may trigger certain tics and behaviours. 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 in are all examples that you may notice could be a reason for an increase in tics.

We do **not** praise a student for not ticcing as this is a completely involuntary condition but we may want to give praise for managing a situation they find tricky or recognising to avoid those triggers that can increase their tics. We want to empower the student to have some self help tools and help them recognise, where possible, to alleviate their tics so that they can be more comfortable at school.

Make a plan. Investigate together what triggers make tics worse, what can help their tics to decrease etc. then once the plan is made, revert to the plan automatically when needed with the least fuss possible as this in turn will give less attention to the tic episodes and in turn should help to lessen the tics.

At school/college we are not just teachers but counsellors to our parents too. Try your best to listen to parents as they will know the children best and try to keep communication open.

Specific Classroom Strategies

- Personal passport/one page profile
- Careful seating plan
- Time out card/leave room/Safe place/tic release
- Step out to self-regulate
- Remove self from area/situation
- Allow movement - Special job/sensory break
- Visual timetables



A personal profile may be something you already have in school/college for all students with SEN and it is very important that any student with TS has one and is involved with the making of this and that all staff members have access to see this. This should involve a list of any possible tics and agreed strategies.

Seating plan is very important to consider. Different students feel comfortable in different places. A student with TS may want to sit at the back of the class so that they can get up and move without being a disruption to other pupils. They may want to sit at the front if they have issues with concentration and want to be helped by the teacher. Or finally, they may want to sit by the door if they have a 'time out card' in use and need access to leave the classroom whenever they feel like they need a break.

If a student is using a time out card it is important that they are not just free to roam the corridors as they like but instead use it as a pass to go to an area in school supported by pastoral staff that will welcome the child and be able to help them relax, release their tics and support them with their work if needed with the expectation that they return to the classroom if possible.

It's important to work with the student so that they know leaving a class is not a punishment but can actually be an effective self help tool/strategy to self regulate their tics as removing ourselves from a situation may be a good thing to do to break a tic cycle.

If a teacher or support staff member sees that a student may be struggling and tics may be prevalent then perhaps they could intervene and provide them with a sensory break or 'special job' for primary age. Distraction is a key with tics so this will help immensely. Brain gym and movement breaks are good for all students so we must try and find time in our timetables to fit these in.

- Feelings chart
- Body maps
- Brain Gym - ([JSJ](#))
- Scale down work amount not difficulty
- Check understanding after class input
- Be consistent and keep expectations clear!



Things like visual timetables are a great tool not just for primary but even a secondary student can have a small one of their own in their diary. Its about knowing what's coming up in the day to reduce any anxieties and feeling in control of themselves.

If a student is ticcing or supressing, it may be that they have not been able to listen to the class input of the lesson. It may be helpful for a teacher or support staff to check understanding before expectations are set in stone.

If a student gets overwhelmed by the busy times of the day for example the start, then maybe providing a member of staff to be able to meet the student 5 minutes earlier to enable them to miss that chaos, go through their timetable and making sure they have their pe kit or maths equipment and are ready for the day so that they are not set up to fail before they have even begun. This also works well for the child that struggles with executive functioning too.

Things to Consider

- A whole school/college approach to understanding Tourette Syndrome can really help a student to feel understood, supported and accepted.
- Awareness assemblies are an effective way to educate other students.
- Consider alternative therapies to help reduce anxieties such as art, music or Lego therapy to aid self expression.
- Nurture programmes and Emotional intelligence training such as:
 ELSA - (Emotional Literacy Support Assistance)
 MISP - (Mindfulness in schools project 7 – 11)
 JIGSAW – secondary
 Thrive approach
- Research free alternative provision: Equine, angling, forest, farm, college



In order for a student to be happy in school/college they need to feel understood, supported and accepted.

We do have peer presentations you can download on our website to help educate students in school/college about TS.

It's important that we help promote self esteem and positive mental health. There are many schemes out there that schools and colleges can sign up to that are very effective. In fact, anything to promote good emotional intelligence, self expression and understanding the behaviours of ourselves and others.

Find out what's available for students that struggling at school/college in your local area. It may be that you have access to a farm, forest school, fishing days, college access days etc. Not all students learn best in the same environment and it may be that these students would benefit from a break in their learning environment. Your local authority should be able to point you in the right direction.

School/College Attendance Issues

There is always a reason for school refusal. Often it's a **can't** rather than a **won't**. Anxiety and exhaustion.

- Attendance officer!
- 5 minute earlier start time (executive functioning skills).
- Gradual integration
- Phased return
- Reduced timetable
- Flexi schooling
- EOTAS/ESCOS



Sometimes students with TS may find attendance tricky due to their tics, exhaustion or anxiety. It's important not to judge parents for their children lack of attendance and to consider this may be down to symptoms of their TS or another medical condition. We understand that attendance is important but we must consider why and put support in place to help them rather than punishing them. It may be that one of the above would suit them better in order to make them successful learners and reach their full potential. It may well be time to consider applying for an EHCNA if you feel extra intervention is needed to make these things available to the student.

Safeguarding

This is a topic you may want to consider very carefully in school or college regarding a student with Tourette Syndrome. Some schools and colleges feel that a student may not be safe in school/college due to the nature of their tics, e.g. self harming. You may need to consider the safeguarding of the other student if too, for example, the student with TS has any swearing or throwing tics. Make sure to consider the following:

- You have a staff member in your pastoral team that has followed this training and will be available for both students and staff to go to if they feel upset by any comments made. Even though students and staff will know this is an involuntary condition it may still be upsetting to hear personal comments.
- Send a letter home to all parents informing them that you have a student in school with TS and that you will provide an information event where they can come and find out more about the condition about how you will be supporting this.
- Risk assessments (pupil led).



No matter how much training staff and pupils have, it can still be hurtful to be the recipient of a tic and this can be very upsetting. It's important that there is someone in the pastoral team that both teachers and pupils can go to if they need to talk about this.

To send a letter home to parents is not standard procedure, however it can be useful if there are any parent complaints or bullying going on. If it is felt by the school/college that this is needed then this would have to be done with the permission of the parents and the pupil involved and a mutual understanding that the reason for this is ultimately to support the child in question. We do have a template letter on request if you need some guidance in this.

It's important that any student is involved in a risk assessment so they too are clear of what the plan is to keep them and others around them safe. Worst case scenario may well be having to leave the classroom and if this is the case, it would need to be made clear to the student that this is not a punishment but an agreed strategy. We do have a template pupil led risk assessment available on request if you feel this would be useful.

Transition

- TS often worsens during the transition to secondary school/college/university or even just a new classroom, teacher or year group. **Environmental factors** can play a huge part in TS. This time can be especially difficult and may well require extra planning and support.
 - Extra visits
 - Talk lots about what's going to happen.
 - Photos of new school and staff – 6 weeks can be a long time out of school/college and routine to get anxious.
 - TA leaflets to give staff at new school/class.
 - Suggest TA training to feeder school/college/university.



We know that transition is a tricky time for all students but especially those of students with TS as we know environmental factors play a huge part in anxiety for these students. Transition is a very anxiety driven time and 6 weeks summer holiday for example, is a very long time to be away from school.

If students are moving to a new school, as soon as you know where they are going feel free to pass them our details so that they can access support for the pupil as soon as possible.

Possible SEN Provisions and Support

- **If** the TS student is on the SEN register they may be entitled to:
 - 25% extra time for assessments/SATS/GCSE's/A Levels
 - Different/quiet room
 - Stop the clock/extra breaks
 - Scribe/reader/laptop/talk to text
- Explore possible adjustments. Find out how best the student learns/records asap! 'Usual way of working'.
- Consider the child's 'usual way of working' ready for exam Access Arrangements.
- EHCP? Communication & Interaction, Cognition & Learning, SEMH, Sensory/Physical.



Not all students with TS will need SEN support but its important if they do, that we explore all possibilities as early as possible.

Most students with TS won't need an EHCP and will be able to manage with the SEN support currently available in school/college but if they do, then it should be supported by what issues are present the most and this may not be tics. Their tics may well be a big part of your evidence but it may be that their co-occurring conditions are of most need.

Explore ways of recording student's work asap. It may be that their tics get in the way of their writing for many reasons. The sooner you 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.

What do our students need?

- To feel understood and supported
- To be accepted by their whole school community
- To not be made to feel different
- To feel safe
- To feel happy
- To know that TS won't stop them in life, they are more than just TS!



Questions to ask yourself

- Are we as a school/college meeting the needs of this student?
- Are we as a school/college doing everything we can to remove any barriers to learning for this student?
- Are we as a school/college providing reasonable adjustments to cater for this student?
- Can we be sure we are not setting this student up to fail?
- Has this student got full access to the curriculum?
- Is this student reaching their full potential?
- Is this student happy to be in school? If not, **why**?
- Is this the right learning environment/setting for the student?



In regards to setting a student up to fail, we mean for example, if a student 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 student's resilience but its also important to pick your battles and consider if certain situations are really necessary?

Is this the right setting for this student? If you have exhausted all other possibilities then this may be something to consider as a last resort. If all these questions have been considered there may well be a time that parents have to ask themselves 'is this the right setting for my child?'

Key take-away points

- 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.
- Never single a student out in class because of their tics.
- Students 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.



<https://www.youtube.com/watch?v=LZQlch6v3W4>

This link is to a video made by Tourettes Action in conjunction with the famous youtuber Caspar Lee to increase Tourettes Awareness. Casper has TS himself so is a great role model for our children and talks to a group of school children about their TS, how it feels and how people can help.



This video was made in conjunction with the famous You tuber Casper Lee. He has TS and helped us create this video and shared it on his YouTube channel as he has millions of followers so it was thought this could increase awareness of TS in a positive way. Casper talks to young people about their experience of having TS.



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twitter.com/tourettesaction

Thank you!



You may wish to look on teacher's page on our website as it is full of many useful resources mentioned in this presentation.

<https://www.tourettes-action.org.uk/62-teachers.html>

If you have any further questions or would like to talk to our Education Manager to discuss a specific pupil in more detail then please feel free to contact Lucy on the above details.