

Supporting Children with Additional Learning Needs (ECEY6006)

Content:

Page 02. AI Statement.

Page 03. Understanding Tourette Syndrome – script.

Page 10. Reference list

AI statement:

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Understanding Tourette Syndrome – script.

Introduction

Thanks Jo, as you can see, I choose Tourette Syndrome (TS, Hereafter) as my ALN to discuss today, coincidentally it is TS awareness month so what better time to talk about it.

TS is a childhood onset neurodevelopmental condition characterised by involuntary movement and noises, which are known as tics (Martino and Pringsheim, 2018). From research in the last decade, it is now more understood to have a genetic basis and more often run in families, (NHS UK, 2025; Johnson *et al.*, 2023; Ganos *et al.*, 2018).

Symptoms typically emerge between the ages of 5 and 7, with tic severity often peaking in early adolescence, a period thought to be influenced by hormonal changes (Ueda and Black, 2021; Stern, 2018). Although TS is a lifelong condition, longitudinal studies show that symptoms frequently improve over time, with around half of individuals experiencing a substantial reduction in tics by early adulthood (Ricketts *et al.*, 2022; Gill, 2020). However, for some individuals, tics can remain persistent and significantly debilitating into adulthood (Ueda and Black, 2021). Up to 80% of children with TS will experience co-occurring conditions, most commonly ADHD, OCD, anxiety or autism, which can have a greater impact on daily functioning and learning (Gunturu *et al.*, 2023; Robertson *et al.*, 2017).

ALN

Under the Equality Act 2010, TS can meet the definition of a disability when tics or co-occurring conditions have a substantial and long-term impact on learning, communication or social participation. However, as TS does not affect cognitive ability, it is not classed as a learning disability (Martino and Pringsheim, 2018). Although, children with TS may meet the ALN Code criteria under the ALNET Act 2018 if tics or co-occurring conditions create learning difficulties that require Additional Learning Provision, such as breaks, adapted tasks or reduced pressure (Lund *et al.*, 2023; Gunturu *et al.*, 2023).

Symptoms (Tics)

Tics are sudden, rapid, recurrent, non-rhythmic movements or vocalisations. They can affect almost any muscle group, including internal sensations such as stomach or jaw tension (NHS Wales, n.d.; Eapen, Cavanna and Robertson, 2016). Tics often come and go, and their frequency or intensity may be influenced by stress, excitement, anxiety, fatigue, or relaxation (Tourette's Action, 2025; Robinson *et al.*, 2017). From onset, they usually follow rostral-caudal progression. Meaning that tic develop in a typical pattern starting with face /head then progress down into the neck, limbs and other parts of the body. Ganos, Münchau, and Bhatia (2014).

Symptoms vary widely, from mild and barely noticeable to severe tics that can be painful or physically harmful, particularly when they involve repetitive or forceful movements. Complex motor tics may even result in self-injury (NINDS, 2025; TAA, 2025). They fall into two categories: simple and complex. Simple motor tics are brief and involve only one muscle such as blink, shoulder shrugging, head jerking. Simple vocal tics (phonic) tics are generally short, meaningless sounds e.g. sniffing, throat clearing, grunting etc. In comparison, complex motor tics are more co-ordinated movements involving groups of muscles, e.g., touching, tapping, jumping, spinning or self – injurious movements (Martino and Leckman, 2022; Robinson *et al.*, 2017). Complex vocal tics are usually words or phrase, sometimes repeating other people's words – echolalia, repeating own words -palilalia. In 10 -15 % of cases this could include the use of socially inappropriate words -this is known as coprolalia. (Efron and Dale, 2018; Stern, 2018; GOSH, 2020).

Identification and Diagnosis

Identification of TS is clinical and based on history and observation. It can be diagnosed by either a neurologist, paediatrician or psychiatrist (Tourette's Action, 2025). Although TS is now understood to have a genetic predisposition, there is currently no blood test, scan or biomarker that can confirm the condition (Gill, 2020).

According to NHS UK (2025) diagnosis of TS requires:

- A child or young person to have multiple motor tics and at least one vocal tic
- That symptoms persist for more than one year
- That onset of symptom began before age 18
- And that these symptoms cannot be better explained by another medical condition

In the UK, diagnosis typically begins with a GP referral to:

- Paediatrics
- Neurodevelopmental services
- CAMHS (especially if co-occurring conditions such as ADHD or OCD are suspected)

Treatment

Although there is no cure for TS, treatment can help manage symptoms. Behavioural therapies such as Habit Reversal Therapy (HRT) and Comprehensive Behavioural Intervention for Tics (CBIT) are recommended as first-line interventions, while medication may be considered in more severe cases or when tics significantly impair daily functioning (NHS UK, 2025; NINDS, 2026).

Prevalence

TS is estimated to affect around 1 in 100 children, meaning it is as prevalent in childhood as autism spectrum disorder (ASD) and childhood epilepsy (Stern, 2018; Tourette's Action, 2025). According to the Tourette Association of America (2025), approximately 20% of children and young people will experience some form of tics at some point in their lives. TS is more common in boys, with estimates suggesting a male-to-female ratio of approximately 4:1, although the reason for this difference remains unclear (Yilmaz and Jankovic, 2025).

Benefit to Diagnosis

A clear benefit of receiving a formal diagnosis, beyond access to treatment, clinical support, therapy, and medication is improved access to community support. When health professionals signpost individuals to face-to-face groups, online communities, and relevant charities, this can significantly enhance support for people with TS and their families (NHS UK, 2025; TAA, 2025). Recent research on online support communities show that these platforms provide valuable information and emotional support, particularly in areas where local services are limited. Such communities help foster a sense of belonging, reduce long-standing social isolation, and contribute to improvements in well-being (Perkins, Coulson and Davies, 2020).

Barriers

One of the biggest barriers affecting children with Tourette's Syndrome is the lack of understanding surrounding the condition (Tourette Action, 2025; TAA, 2025). This lack of awareness of the condition contributes to misconceptions and stigma, which can significantly impact a child's wellbeing (Efron and Dale, 2018; Kallol, 2021; TAA, 2025). Children may feel embarrassed, ashamed or isolated because of their tics. Some avoid social activities, while others attempt to suppress their tics in situations where they feel their tics are not socially acceptable (Ricketts *et al.*, 2022; Perkins, Coulson and Davies, 2020). Unfortunately, this can give the false impression that they can control their tics or that their symptoms are mild. In reality, tic suppression requires intense concentration and effort, often leaving children exhausted or even in pain, with many also experience rebound tics, which are more forceful and can last for hours without relief (Tourette's Action, 2025; Matsuda *et al.*, 2016). According to Great Ormond Street Hospital (2025), learning about the condition should be the first point of supporting a child with TS. This includes educating family, friends and teachers on how TS affect a child and what can be done to support them. This aligns with Ricketts *et al.* (2022) research outcomes that highlight that understanding teachers, flexible expectations and inclusive practice increases children's outcomes and reduces the pressure to suppress tics.

Another significant barrier for children with TS is access to clinical support and treatment. According to NHS UK (2025) guidance, parents are advised to consult a GP if they suspect their child has TS. GPs may then refer the child to specialist services such as neurology or paediatrics for further assessment and interventions, including behavioural therapy. Jankovic (2017) states that numerous studies provide evidence that behaviour therapies are effective in patients with TS, this includes research by Ueda and Black (2021) showing that behavioural therapy can reduce the frequency, severity, and urges associated with tics in approximately 74% of cases. However, in contrast to this, the National Institute for Health and Care Excellence guidance NG127 on suspected neurological conditions does not recommend routine referral for tic disorders unless there are concerns about co-occurring conditions such as ADHD or anxiety (NICE, 2023). Furthermore, there are currently no dedicated NICE clinical guidelines specifically for diagnosing or treating TS, a gap highlighted by Tourette's Action and acknowledged in recent parliamentary discussions (UK Government, 2025). In addition to the lack of national guidance, a recent Freedom of Information request submitted to Cardiff and Vale University Health Board revealed that there are no dedicated Tic Disorder clinicians offering specialist provision within the Children, Young People and Family Health Services (CYPFHS) Directorate (NHS Wales, 2024). This does not appear to be an isolated issue. Jeayes *et al.* (2023) found that only two areas of the UK currently offer standalone services for children with tics, with most regions providing only signposting to self-help resources or voluntary sector organisations.

Medial v Social Models

When we think about TS, the medical model helps us understand the neurological basis of tics and why some children may need clinical or therapeutic support (NHS Wales n.d.). However, the ALN Code in Wales is grounded in the social model of disability, which emphasises that it is often the environment, not the child that creates barriers to learning (Welsh Government, 2021).

Strategy

Environmental adaptations in the classroom for children with TS can make a significant difference to their learning outcomes, as tic severity is strongly influenced by stress, sensory load and social pressure (Carter *et al.*, 2020; Wadman, Glazebrook and James, 2016). Even small adjustments such as seating a child at the edge of the classroom so they feel less self-conscious than when seated at the front can have a positive impact. Offering access to a quiet breakout space and reducing exposure to sudden loud noises can help minimise tic triggers and improve comfort (Efron and Dale, 2018; Tourette's Action, 2024). Reducing social pressures, allowing brief movement breaks and providing alternative ways to participate can also significantly reduce anxiety (NHS UK, 2025; Lund *et al.*, 2023; Gunturu *et al.*, 2023).

For children with physically intense or potentially harmful tics, ensuring adequate space, providing safe equipment and adjusting physical activities can reduce risk and discomfort (Robinson *et al.*, 2017; Tourette's Action, 2024). Staff awareness and whole-school understanding are equally essential, as informed teachers are better able to recognise triggers, understand the effort involved in tic suppression and respond with empathy and flexibility (NHS UK, 2025; TAA, 2025). Collectively, these environmental adjustments foster a more inclusive and supportive learning environment, contributing to improved wellbeing and a stronger sense of belonging for pupils with TS (TAA, 2025). Creating social safety and ensuring that pupils feel valued aligns closely with Maslow's Hierarchy of Needs, which emphasises belonging as a foundation for learning and self-esteem. This is supported by Kallol (2021) argument, that children who experience shame or sadness are more likely to struggle academically, highlighting the importance of emotional security and acceptance in educational settings.

Conclusion

In conclusion, TS is a common neurodevelopmental condition, yet children and young people continue to face significant barriers due to misunderstanding, stigma, and inconsistent access to specialist support. Although many children experience tics at some point in their lives, a lack of public awareness often leads to shame, isolation, and harmful attempts to suppress tics, which can worsen symptoms and impact wellbeing. National guidance adds further complexity: This gap in policy, combined with limited specialist services across the UK, contributes to delayed identification and unmet needs. Improving awareness, strengthening referral pathways, and ensuring equitable access to specialist support are essential steps in promoting better outcomes for children with TS.

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