Nursing Children and Young People

Tourette Syndrome- Challenging Misconceptions, Improving Understanding

--Manuscript Draft--

Manuscript Number:	NCYP1416R2
Article Type:	CPD
Full Title:	Tourette Syndrome- Challenging Misconceptions, Improving Understanding
Corresponding Author:	Mark Freeman-Ferguson, MSc Edinburgh Napier University - Sighthill Campus Edinburgh, UNITED KINGDOM
Abstract:	Tourette Syndrome (TS) is a neurodevelopmental/ neuropsychiatric tic disorder, affecting around 1% of the school-age population. Children and young people with the condition exhibit involuntary motor and vocal/ phonic tics. Only 10% of those with Tourette Syndrome have Coprolalia. Tourette Syndrome often presents with other conditions, such as Obsessive-Compulsive Disorder, Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder. The impact of the condition on the child and young person is multi-factorial and individual to the person affected. Nonetheless, there is a common thread of impulsivity, anxiety, and mental ill-health. Those affected may be able to manage the condition with little/no professional support, but some may need pharmacological and non-pharmacological support, particularly mental health support. It is essential that peers, teachers, healthcare staff and society in general have a good knowledge and awareness of Tourette Syndrome to ensure children and young people living with the condition are supported with compassion and acceptance.
Keywords:	Tourette Syndrome; tics; mental health; child health; impact; empathy; compassion
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Abstract

Tourette Syndrome (TS) is a neurodevelopmental/ neuropsychiatric tic disorder, affecting around 1% of the school-age population. Children and young people with the condition exhibit involuntary motor and vocal/ phonic tics. Only 10% of those with Tourette Syndrome have Coprolalia. Tourette Syndrome often presents with other conditions, such as Obsessive-Compulsive Disorder, Autistic Spectrum Disorder and Attention Deficit Hyperactivity Disorder. The impact of the condition on the child and young person is multi-factorial and individual to the person affected. Nonetheless, there is a common thread of impulsivity, anxiety, and mental ill-health. Those affected may be able to manage the condition with little/no professional support, but some may need pharmacological and non-pharmacological support, particularly mental health support. It is essential that peers, teachers, healthcare staff and society in general have a good knowledge and awareness of Tourette Syndrome to ensure children and young people living with the condition are supported with compassion and acceptance.

Word Count: 5327 (includes abstract, reference list, tables and time outs)

Author details

Mark Freeman-Ferguson, Lecturer (Child Health Nursing), Edinburgh Napier University, Sighthill Campus, Edinburgh, Scotland.

Keywords

Tourette Syndrome, tics, mental health, child health, impact, empathy, compassion.

Tourette Syndrome: Challenging Misconceptions, Improving Understanding.

Background

Tourette Syndrome (TS) is a neurodevelopmental/ neuropsychiatric tic disorder (Baldermann et al 2016). It is associated with motor and vocal/ phonic tics and is often co-morbid with other conditions such as Obsessive-Compulsive Disorder (OCD), Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD) (Walter and Vitek (2012); Freeman (2015), World Health Organization (2020)). The condition affects approximately one in one hundred school age children and is more prevalent in boys (75%) (Tourettes Action 2020a, 2021a).

TS is a largely misunderstood condition in society, often being inaccurately associated with people who repeatedly swear or say inappropriate phrases and is commonly joked about in the wider community (Fat et al, 2012; Calder- Sprackman et al 2014). There is a 'lack of information, knowledge and awareness about TS in the community, including among health professionals.' (Eapen et al 2016 p. 2). Greater understanding of the condition and its impact on the child, young person and their family will promote a more accepting, empathetic, and compassionate approach to their health and social care.

Aim

The aim of this article is to provide health and social care staff with greater knowledge and understanding of TS and its impact, whilst dispelling some of the myths surrounding the condition. This article also aims to encourage a more accepting, empathetic, and compassionate approach towards children, young people and families living with Tourette Syndrome.

Why should you read this article?

To improve your knowledge and understanding of Tourette Syndrome (TS)

- Define what Tourette's syndrome is and how it might relate to other mental health co morbidities
- Describe different types of tics and their impact on children and young people.
- Explore through a case study exercise [redacted] how living with Tourette Syndrome impacts the child, young person and their family's day-to-day life and mental health.
- Foster greater acceptance, empathy and compassion towards children and young people who live with Tourette Syndrome.
- Understand the importance of nurses in supporting children, young people and their families living with Tourette Syndrome.

Time Out 1
Before beginning, take some time to consider what you believe to be the signs and symptoms of Tourette Syndrome and the impact they may have on the child or young person and family. Make a note of them, before comparing your thoughts with the information in the article.

Diagnosis

Currently there are no blood tests, scans, or other such tools to diagnose TS. Consequently, diagnosis is usually made via a GP referral to a neurologist, psychiatrist or paediatrician (Tourettes Action (2021b), who considers the history and presentation (Singer et al 2016). For TS to be diagnosed, the child or young person:

1. Must have motor and vocal/ phonic tics,
2. Which must have been present for at least one year.
3. However, they may not manifest concurrently or consistently. (WHO 2021)

A tic can be described as 'a stereotyped (but not by everyone), repeated (but not rhythmic), usually rapid and brief movement or vocalization' (Freeman 2015 p8). TS is very much a condition that affects each person differently and there is no way to predict the presentation, progression, or prognosis of the tics, which are likely to wax, wane and change as the child/ young person grows (Freeman 2015).

Aetiology and Pathophysiology

TS has a complex, multi-faceted relationship between the environment and the child's genetic profile, the aetiology of which is largely unknown. There is some evidence to suggest a genetic component. For example, twin studies show more than 50% of both identical twins had TS, whilst only 10% of both fraternal twins had the condition (Bernard et al 2012). That said, no single direct genetic link has yet been identified. Additionally, it is known that genetics cannot be the sole reason for developing the condition, otherwise there would be a higher incidence of both identical twins having the condition (Freeman, 2015). The environment may also play a part in the development of TS, but the connection between this and genetics is not fully understood (Freeman 2015).

The pathophysiology is also largely unknown. There are differing theories which suggest involvement of the basal ganglia, neural networks, thalamus, dopamine, cortisol and pre-synaptic abnormalities (Walter and Vitek, 2012, Lakraj et al 2014), amongst others. However, a clear and definitive pathophysiology has yet to be established. What is generally accepted is that the condition is no longer considered solely a psychiatric condition, instead it is more likely a combination of different pathologies.

Signs and Symptoms

The signs and symptoms of TS form the basis of the diagnostic criteria. Tics can take many forms but are subcategorised as simple and complex (see table 1) and all are unpredictable in nature (Dempsey et al 2018). Environmental factors and activities that increases stress and fatigue tend to exacerbate the severity of the signs and symptoms (Caurin et al (2014); Barnea et al (2016).

Table 1- Examples of Tics

	Motor Tics	Vocal/ Phonic Tics
Simple	Eye blinking Eye rolling Nose twitching Grimacing Shoulder shrugging Limb and head jerking Abdominal tensing Lip pouting Head turning Frowning	Whistling Throat clearing Sniffing Coughing Tongue clicking Grunting Animal sounds Hissing
Complex	Jumping Hopping Twirling Clapping Touching objects Touching other people Obscene movements or gestures (Copropraxia) Repeating other people’s gestures (Echopraxia)	Uttering words or phrases out of context Mimicking accents Unusual rhythms, tone, or volume Saying socially unacceptable words (Coprolalia) Repeating a sound, word, or phrase (Echolalia)

Chowdhury and Murphy (2017), Tourettes Action (2019)

Over 80% of people living with TS feel a premonitory urge (sensation, impulse or tension) that immediately precedes the tic (Cavanna et al 2017). The urge is only relieved when the person tics, whilst suppressing the tic will often increase the urge. Many feel the urge is only relieved if the tic is done “just right” (Chowdhury and Murphy (2017 p21), leading to repeated tics until the satisfaction is felt. All of which is exhausting, debilitating and exacerbates pain and discomfort (Pittenger 2017).

Motor tics usually present from around 5-6 years of age and children tend to present initially with one simple motor tic, such as flicking hair or blinking. This tic is likely to disappear only to be replaced by a different tic, followed by the introduction of vocal/ phonic tics. The severity and complexity of the tics is likely to continue to worsen through the pre-pubertal stage of development (ages 10–12 years), when the tics are at their most unstable. Around puberty the tics often begin to stabilise but are unlikely to lessen, reaching most stability around early adulthood (Freeman 2015). In some cases, the tics lessen or even stop in adulthood (Chowdhury and Murphy 2017). Equally, the tics may continue throughout the lifespan. Consequently, ensuring the child/young person has a positive association with their TS will help them be more confident in living with the condition long-term.

Despite Freeman's (2015) definition, not all tics are externally performed. Children and young people often also live with more hidden tics, such as mental tics, thought tics, conversational tics, suggestive tics, and handwriting tics (Table 2). The evidence base around this is sparse and needs more detailed exploration. These are more likely to take place internally and are often more disturbing than the motor/ vocal tics. Children and young people with TS often suffer from intrusive or disturbing thoughts, such as thoughts about hurting others or themselves, the need to count objects or steps, an overwhelming need to behave in a certain way that is usually socially unacceptable in society (Tourettes Action 2020a, 2020b).

Table 2- Examples of Hidden Tics

Hidden tics	Examples
Intrusive thoughts	Usually negative and disturbing thoughts.
Mental tics	Conscious repetition of words, phrases, sounds in the mind, e.g., repeatedly thinking about a sentence.
Thought and Conversational tics	The overwhelming urge to tell the truth about something or say something inappropriate or offensive, irrespective of the consequences, e.g., impulsively telling a teacher they have body odour. Where most neuro-typical children will only think these thoughts, children with TS have the overwhelming impulse to say them.
Suggestive tics	The overwhelming urge to undertake actions that are prohibited, e.g., running in school, pressing the fire alarm.
Handwriting tics	Repeated writing of the same word or sentence, outlining each letter multiple times, pulling back the pen when writing.

Murphy and Muter (2012), Burd (2014), Zanaboni Dina (2016), Tourettes Action (2019, 2020)

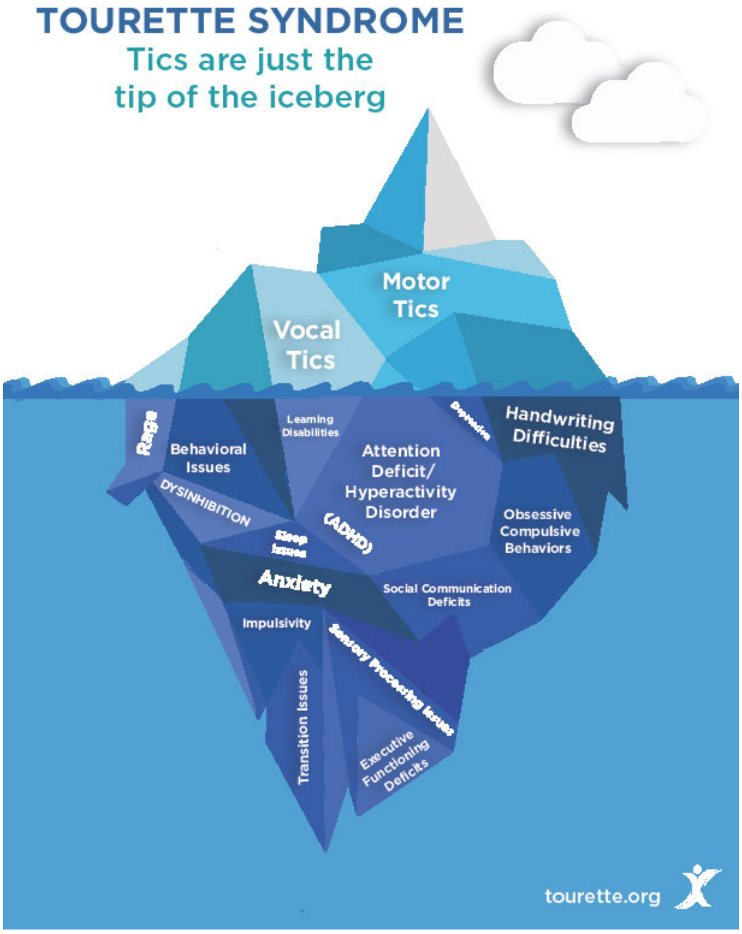
There is a general societal misconception that children and young people with TS swear uncontrollably or say socially unacceptable words (known as Coprolalia). Less than 10% of people with TS have coprolalia, and even then, it may be transient (Freeman 2015, Pittenger 2017, Tourette's Action 2020b). Coprolalia is rare and is not considered a diagnostic symptom of TS (Chowdhury and Murphy 2017).

Time Out 2
Pause for a moment to reflect on the implications of hidden tics. If you suffered from the same how isolated or vulnerable might you feel? Could the compulsive nature of these leave you doubting your ability to reason, question which thoughts are real and true? Children learn incrementally that such tics make them different to others. Make a note of why you might need to hear patient's lived experiences of this, as part of ensuring a more empathetic and family centred care approach to your work.

Co-Morbidities

As the Tourette Association of America poster below demonstrates (see figure 1), the tics are just the tip of the iceberg in TS. Around 80%-90% of children and young people with TS also have at least one associated co-morbidity (O'Hare et al 2016). The most common comorbidities of TS are Attention Deficit (Hyperactivity) Disorder (ADHD), Obsessive Compulsive Behaviour or Disorder (OCB/ OCD) and Autistic Spectrum Disorder (ASD). Other coexisting conditions include anxiety, depression, oppositional defiance disorder, bipolar affective disorder, conduct disorders, intermittent rage, impulse control, self-injurious disorders and sensory issues and tics (Hallett 2014, Eapen et al 2016, O'Hare et al 2016).

Figure 1: Co morbidities that may exist in association with tics



Used with the kind permission of Tourette Association of America (2021)

Psychosocial Impact

TS can be a debilitating condition, and whilst many will only have minor tics, which they will be able to suppress for short periods and/ or adapt to their circumstances, many will have more complex tics that cause physical pain or discomfort (Efron and Dale 2018). TS, in combination with comorbid symptoms, such as distractibility, impulsivity, inability to focus and obsessive thinking and behaviours, mean the child or young person has an increased likelihood of having more challenges in their day-to-day life than most of their peers. This generates an increased probability of lower self-esteem, poorer psychosocial functioning, poorer overall quality of life, depression, fatigue and social isolation (Eapen et al 2016, Tourette's Action 2020b). Many children with TS face teasing and bullying, not only from peers but also from adults (including teachers) who do not understand the condition (Dempsey et al 2018). The impact of having TS and comorbid conditions can be overwhelming at times.

The tics, compulsions, behaviours, and other people's reactions can also be overwhelming for the parents/ caregivers and other family members, especially siblings, who can often feel left out when much of the parents' attentions are on the child with TS

(Freeman 2015). The irregular, unpredictable nature of TS along with the waxing and waning of the condition can be unsettling for parents/ caregivers. This combined with the stigma around the condition, means they may live with overwhelming sadness, worry, fear, even guilt, which can affect their mental health and ability to cope.

Time Out 3
To gain a better understanding of the day-to-day lived experience of children and young people living with TS, imagine you are a teenager, and you develop an itch on your right deltoid muscle. You feel the urge to scratch it, whilst out food shopping with your parents. You reach over, scratch it, and alleviate the itch, only for it to return a few moments later and for the process to start all over again. Now you are exhibiting slightly exaggerated, unusual, repetitive movements, and, in the process, people start staring or pointing at you, whispering about you, some may be mocking you or tutting and shaking their heads. You become increasingly aware of other people's attentions, so you try to suppress the need to scratch, but that makes you more self-conscious and in trying to ignore the itch you are less able to focus on other aspects of your life, like where you are walking, what your parents are saying. You then start to move your shoulder and arm in the hope the movement of the fabric will alleviate the itch, but that just brings more unwanted attention, so you try to hold it all in. This means by the end of the day you are exhausted and in pain from tensing your deltoid and shoulder to try to minimise the itch. Now imagine feeling like this for most of the day, every day.
Consider for a moment, how this might make you feel physically, mentally, and emotionally, in the short and long term? How would you feel about presenting yourself to others and risking their judgements? Would you avoid such interactions or rehearse explanations for your behaviours?

Childhood and adolescence can be a difficult time for children and young people for many reasons, especially at school, but anything that makes a child stand out, be it race, religion, wearing glasses, colour of hair, sexual orientation, or indeed having tics makes it more likely that they will be bullied (Malli et al 2016, Young Minds 2021). Teasing and bullying add another layer to the daily challenges of someone with TS.

Whilst children and young people's level of intelligence tends to be similar to those who do not have TS, they can have learning differences or difficulties, caused by the tics, management of the tics or co-morbid conditions that can make learning difficult (Centers for Disease Control and Prevention (CDC) 2021). To improve teacher understanding, NICE (2019) advises parents and carers of children and young people with TS to inform the school that they have tics, that these are involuntary and cannot be stopped thereby minimising the chance of the child being reprimanded. Teachers can then put measures in place to support the child or young person. Dempsey et al (2018) also suggest that children and young people with TS learn the appropriate language to use to explain the condition when asked by peers or adults, see Table 3 for some commonly asked questions and suggested responses.

Table 3- Commonly Asked Questions and suggested responses
Q: “Why do you do that?” or “Why do you make that noise?” A: “I have a condition called TS and sometimes I make sounds or movements called tics. It’s not contagious and you can’t catch it from someone who has it. No one knows the direct cause of TS.”
Q: “What’s it like to have TS?” A: “You can think of tics in the same way that you think of hiccups. You don’t know when they are going to show up, and you can’t force them to go away. They can be annoying and even uncomfortable at times, but they’re not dangerous.”
Q: “How do we respond to you when you do that or make that noise?” A: “The best thing that you can do is to just ignore my tics. So, this means that when you see one of my tics in action, try not to talk to me about it or look at me while it’s happening.”
Q: What should I do when people laugh at me and call me names? I’ve tried walking away, but they follow me. I’ve tried telling the teaching but they make fun of me for that too. A: Try challenging them by asking “so what?”, “Maybe I do make those noises, but who cares?”
(Adapted from Dempsey et al 2018, p144)

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To gain a better understanding of the daily struggles of children and young people with TS in a classroom setting, continue with the scenario in Time Out ~~5~~ 4.

Time Out [redacted] 4
The itch is back. You are trying to sit quietly in class, so as not to draw attention to yourself, but the itch is so bad it is impossible not to try and scratch. Holding it in makes it painful as your whole-body tenses. So, instead of paying attention to the teacher and learning what you need to in the classroom you are so focused on suppressing your need to scratch or looking around to see if anyone is watching you and hoping that someone won't see you, meaning you start to fall behind in your schoolwork. This increases your stress, anxiety and then exacerbates your tics. It's cyclical. Given that you live with co-morbid conditions, ADHD, OCD and anxiety disorder, meaning you lose concentration frequently, have difficulty focusing, worry about what others might think of you and have frequent intrusive thoughts, the classroom can feel a challenging and overwhelming place.
As you grow with your TS, you learn about your own compulsive thoughts and behaviours incrementally and usually in relation to others' negative reactions. How do you think this could affect the normal stages of biopsychosocial development in childhood?

As can be seen from the common example above, TS is multifaceted and multi-layered, including co-morbidities and co-existent problems, such as depression, anxiety and low self-esteem, all of which often lead to more negative psychosocial impact and reduced ability to learn and therefore a lower quality of life (Eapen et al 2016). The consequent impact on mental health can be significant and affect normal day-to-day functioning, for all family members, not just the child or young person.

One in nine of all children in England has a mental disorder between the ages of 5 and 15 years and half of all mental health problems are diagnosed before the age of 14 years (NHS England 2019). As such, the improvement of children and young people's mental health is internationally recognised as a health priority (WHO 2019). In recent years there have been reviews of children and young people's mental health service provision across the four nations of the UK, with governmental pledges to increase funding and direct it to the most needed services. Whilst there is generally more focus on the biopsychosocial impact of conditions such as ASD and ADHD, TS often has a profound effect on the child, young person, and family. TS is often missed as a diagnosis, one that needs additional ongoing psychosocial support. This means there is significant variability and inconsistency of support services across the NHS (Hollis et al 2016). As such there needs to be a collaborative, multiagency undertaking to create a more streamlined approach to diagnosing and supporting children and young people with TS, such as a national care pathway.

Management and Nursing Care

The main aim of the management of TS is to assist the child and family to accept and live with the condition (Freeman 2015). This may involve psychoeducation, medication, talking therapies, and/ or behavioural therapies. Most children and young people manage their TS with no medication or specific treatment (Wu and McGuire 2018). However, there are some who require ongoing healthcare interventions (pharmacological and non-pharmacological, such as behavioural and talking therapies).

Whilst advances in pharmacology continue, there are still significant side effects to most TS medications that have an impact on children and young people's day-to-day lives. Due to the unpredictable nature and the diversity of tics in the TS population, there is not one medication that suits all (Saggu et al 2018). Children may need to try a few before finding one that is suitable, and even then, it may not be suitably effective.

Behavioural therapies (see table 4) and talking therapies aim to encourage the child, and their family to have a positive association with their TS. Some also aim to help the child become aware of the premonitory urge and tics, have some ability or control over them, modify the behaviour or reduce their severity. (Ricketts and Bauer 2018, McGuire et al 2018).

Table 4- Behavioural Therapies	
Comprehensive Behavioural Intervention for Tics (CBiT)	A toolkit of behaviour management techniques (https://www.tourettes-action.org.uk/71-behavioural-therapies.html)

Habit Reversal Therapy	A technique to help the child to recognise the tic, where it comes from, gain some control over the premonitory urge, and create a competing response thereby preventing the tic.
Exposure and Response Prevention	Encourages the child to tolerate the premonitory urge at its worst to normalise it and reduce the need to tic.
Psychoeducation	Gaining a greater understanding of TS, including causes, pathophysiology, usual course of tics and co-occurring conditions. This encourages the child to be more confident in their knowledge and normalise the condition.
Functional Intervention	Helps the child identify the environmental sources that exacerbate their tics to minimise their impact.
Social Support and Reward System	A support and reward system to encourage the child to gain a better understanding of how to control their tics.
Relaxation Training	Reduces stress, which can reduce tics.
(Tourette's Action 2021c)	

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Whilst medication and psychological/ behavioural therapies have their place in helping the child to manage their TS, nurses play a pivotal role in helping children understand and live with their condition, be it in the community or an acute setting. Nurses are at the forefront of healthcare provision, meaning they are the main providers of kind, respectful and compassionate care, whilst being an advocate for the child and family (NMC 2018). Encouraging the child to narrate their experiences and by actively listening to those experiences the nurse can help the child to better articulate their needs in healthcare, school, peer groups and the wider community. With space and time to build a trusting, therapeutic relationship, in conjunction with a greater understanding of the impact of living with TS, the nurse is ideally placed to help the child explore their everyday challenges and assist them in finding solutions to those challenges. Rehearsing responses to comments, questions or peer behaviours can empower the child and improve their confidence (Dempsey et al 2018). Ultimately, improving knowledge would foster wider societal understanding thereby engendering more empathetic, supportive responses towards people with Tourette's Syndrome.

Summary and Implications for Practice

TS is a multi-layered, complex condition that can be very challenging to live with for children, young people, and their families. The motor tics are exhausting, the vocal tics are embarrassing, and the mental tics are draining. It is a condition from which the child or young person can get little or no relief. It can cause isolation, fear, and potentially suicidal ideation. As nurses, we care deeply about the children and young people in our care and want the best for them. However, a lack of basic knowledge and understanding of TS in healthcare often leads to delayed or no diagnosis or a lack of compassion in the care delivered. Many ask the child or young person to stop ticcing, which is like asking someone to stop blinking.

Despite the incidence of TS being similar to that of other neuro-diverse conditions, it is generally less well understood and tolerated by healthcare staff and wider society. A good knowledge base of the presentation, impact and management of TS and the use of compassion and understanding when caring for people affected is essential to providing children and young people with a positive perception of their condition and a greater likelihood of self-acceptance. Nurses have a pivotal role to play in ensuring children and young people have positive and beneficial experiencies when working with healthcare professionals.

Time Out ■5
Finally, compare the signs and symptoms of Tourette Syndrome that you wrote down prior to reading this article and compare with your knowledge now.
Write down at least five important points you have learned from this article.
If you would like additional information or support in caring for children and young people with TS, please use the links below. Tourettes Action https://www.tourettes-action.org.uk/

Tourette Scotland	https://www.tourettescotland.org/

Key Points

1. The child or young person must have had motor and vocal/ phonic tics for a minimum period of 12 months to be diagnosed with TS.
2. Children and young people with TS may also have less obvious (hidden) tics and most will have other co-morbidities and co-existing symptoms and may require referral to specialist services for physical or mental health support.
3. Most children and young people do not have Coprolalia (involuntary swearing and inappropriate language).
4. Children, Young People, and their families need understanding, acceptance, compassion, and support to help them cope with living with Tourette Syndrome.

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Queries Regarding Revisions

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