

TOURETTE SYNDROME

INCLUSIVENESS

' I hope that people accept me for who I am, and that I don't have to be these other people, I can just be me. I want other people to think: Oh, she's really cool - she's my friend, she has Tourette Syndrome, whatever.'

- Amanda

The Aim of Scouting is to promote the development of individuals, enabling them to grow and take their place in society as active citizens. As we move forward with the Canadian Path we are much more aware of each individual's personal progression, inclusive of their varying abilities. This inclusiveness within Scouting uniquely positions us to play an important role in modifying community attitudes and behaviour towards individuals with identified needs; it starts with Scouts.

Please use this guide for a better understanding of youth with Tourette Syndrome; how as Scouters, we can make a difference through simple interventions, program modifications and knowing where to get help when needed.

DESCRIPTION

Tourette Syndrome (Tourette) is a neurological disorder; this means it affects the nervous system. It is a condition that causes you to have repetitive, involuntary movements or noises called tics, for example, repeated blinking, repeated throat clearing, repeated head nodding, etc. A tic has no purpose and, in general, you cannot help doing it. The early symptoms of Tourette are not always noticed and as such, Tourette is often un-diagnosed (or mis-diagnosed). The average onset is between the ages of 4 and 7 years. Children may be diagnosed with a tic disorder if they do not have all the criteria for Tourette.

Most people with the condition experience their worst symptoms in their early teens, with improvements occurring in their late teens and continuing into early adulthood. Males are affected by Tourette about 3 to 4 times more often than

females. It may be associated with various other identified needs such as behavioral problems and Attention Deficit Disorder (ADD). It can often be well managed with psychological treatments, and sometimes medication. There are varying degrees of the syndrome, it is not infectious and others cannot catch it by contact or association!

CHARACTERISTICS/BEHAVIORS

- Motor tics include things such as blinking, head nodding and turning, kicking, pouting, facial grimacing, twitches, etc.
- Vocal tics include things such as sniffing, clearing of throat, coughing, screaming, tongue clicking, vocalizing animal sounds, etc.
- Mimicking what others do and say (Echolalia)
- Expressing comments that are personal and rude, and shouting involuntary obscene swear words (Coprolalia); the involuntary swearing only occurs in approximately 1 in 10 children with Tourette.
- It is vital to understand that this involuntary swearing in no way characterizes the upbringing or moral disposition of the youth

Associated Disorders:

- Up to 8 in 10 youth with Tourette will also have some degree of behavioral identified needs;
- Obsessive Compulsive Disorder occurs in about 5 in 10 youth with Tourette
- Attention Deficit Disorder occurs in about 6 in 10 youth with Tourette
- Learning Disabilities occur in about 3 in 10 youth with Tourette
- Mood Disorders such as Depression or Anxiety occur in about 2 in 10 youth with Tourette
- Conduct Disorders occur in about 1-2 in 10 youth with Tourette
- Self-injury Behaviours such as head banging occur in about 3 in 10 youth with Tourette



IN A SCOUTING SITUATION

- Avoid making the youth with Tourette a focal point of attention in relation to the other youth and do not focus on the tics carried out by the youth
- Allow the youth the opportunity to exit the hall (safely and in sight) for privacy if the tics are becoming overwhelming
- Monitor the youth with Tourette for possibilities of bullying behavior on the part of other youth, such as ridiculing, teasing and laughing at the youth
- If tics are experienced by the youth, search for alternate, collaborative ways to assist the youth in functioning around them when carrying out group activities
- If writing is a challenge, can the youth with Tourette have access to a computer keyboard or a recording device?
- Most youth with Tourette respond well to positive parenting techniques
- Focus on the youth doing the right thing and not the wrong thing; place the emphasis on praise not consequences
- Remember that the tics or behaviours are involuntary and not done on purpose.

PROGRAM MODIFICATION SUGGESTIONS

- Educate the other children on the dynamics and scope of Tourette
- Provide a structured setting of adult supervised support for the youth with Tourette to avoid inappropriate, negative reactions on the part of the other youth
- Allow more time and mentoring support for the youth with Tourette to process detailed work required for badge work, crafts and other program activities of a similar nature
- Rather than focus on performance outcome, explore with the youth with Tourette what is manageable for them, to avoid the youth feeling overwhelmed to function at an unreasonable expectation level
- Consult with the parents and the youth with Tourette on an ongoing basis to determine what works best for them in the group setting and the program
- Consider judiciously incorporating a reward system - but don't have the youth depend on it
- Develop the Code of Conduct with both the inclusion of the youth and the leadership team

FURTHER ASSISTANCE

This Info Sheet is a resource guide only and is not intended to be therapeutic, diagnostic, medical, or legal advice. Our best source of assistance for youth with identified needs is the youth's parents or caregivers; the information provided is designed to support the relationship that exists between a youth and his/her parents or healthcare providers and the Scouters involved with the youth.

SOURCES

<https://www.facebook.com/TouretteCanada>, Tourette Canada and material adapted and used by permission of The Scout Association (UK), Scouts Australia, and Scouting Ireland.

