



INCLUSIVE 4-H: TOURETTE SYNDROME

WHAT IS TOURETTE SYNDROME?

Tourette syndrome is a neurological disorder that involves repetitive movements or unwanted sounds (tics) that cannot be easily controlled. Tics typically show up between ages 2 and 15, with an average being around 6 years old. Tics may go away with age, but some people experience tics their entire life. Some people may also improve control over their tics as they get older.

Tics (sudden brief, intermittent movements, or sounds) are the main sign of Tourette syndrome. Tics will vary in type, frequency, and severity. Tics may worsen if the person is sick, stressed, tired, anxious, or excited. Tics also change over time. Someone with Tourette syndrome may develop and/or lose different types of tics frequently.

Tics can range in severity from simple to complex. Simple tics may include rapid blinking, shrugging, repetitive throat clearing, or grunting. Complex tics are defined by coordinated patterns of movements using multiple muscle groups or vocal tics that include repeated words or phrases. Simple tics are much more common in people with Tourette syndrome than complex tics.

Although someone with Tourette syndrome may be able to suppress or camouflage their tics, they cannot make them go away completely. If the person spends a lot of energy suppressing their tics or they are in an especially triggering situation (e.g., the environment is causing anxiety or stress), the person may experience an “attack” where many tics control their body for several minutes. People with Tourette syndrome often lead healthy, active lives.

IMPORTANT CONSIDERATIONS

- Have contact information for parents or guardians and the member’s doctor in accessible places. An example of this would be behind the child’s nametag and in the medical forms box which should be stored in the main office at 4-H events. This form should include information such as what kinds of medications the child is taking, allergies, if any adaptive devices are used, and other health conditions.
- Understand that some people may not feel comfortable talking about certain aspects of their condition or disability. Do not force someone to answer questions that make them uncomfortable. Remind them that any information they share is

voluntary, confidential and not required. Learn what the member enjoys and try to weave that into the 4-H experience (e.g., including their favorite food as a snack, having their favorite color marker for craft projects, etc.)

- Visit with the member and his or her parent(s) to find out more information about the member and their Tourette syndrome. Questions that can be asked include:
 - a. What can we do to make the 4-H environment inclusive for you?
 - b. What can we do to help you feel comfortable during 4-H activities and events?
 - c. How would you like us to support you if you are in a stressful/triggering situation?
 - d. Are there certain things we can do/not do to support you?
 - e. If you do experience tics during a 4-H event/activity and others ask questions, is there a certain way you feel comfortable with us responding?
- Unless the child's tics are extremely disruptive to the event/activity, do not remove them from participation. If his or her tics are becoming disruptive, allow him or her to excuse themselves to another room momentarily.
- Use patience when interacting with a child with Tourette syndrome. Understand that they cannot control some of their words or actions. Do not ridicule or reprimand a member with Tourette syndrome when he or she displays a tic.
- Allowing the member to have a fidget device and/or headphones may help keep their energy controlled during settings where they will be sitting for long periods of time. Ask the child if there is something he or she uses during school to help with focus.
- Some tics may result in self-harm or harm to others (e.g., head banging, hitting, or biting). If a child is presenting harmful tics, it may be helpful to intervene to attempt to stop the harmful situation. The conversation you have with the child and his or her family members early on will help you to determine the best ways to intervene in harmful situations.
 - a. The person may have ways to control for these tics as well, such as wearing biting necklaces or carrying a pillow
 - b. Harmful tics are not common in people with Tourette syndrome, but it is still an important consideration.

ADDITIONAL RESOURCES

- <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Tourette-Syndrome-Fact-Sheet>
- www.tourette.org

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