

TOURETTE SYNDROME



Tourette Syndrome (TS) is a condition in which people make repeated and sudden movements or sounds in response to a strong urge to do so – what is called a “tic.” The urge they feel is much like the need to sneeze and producing the tic relieves their discomfort. The tics usually can be suppressed with effort. If the person concentrates on doing something else, the need to produce a tic can be reduced.

Most tics tend to start first in the head and face. Children with TS often blink their eyes, frown, or sneer. Some children repeatedly clear their throat, yelp or yell, or make noises like tongue clicking (vocal tics). They may imitate sounds, or the speech or actions of other people. A small group of individuals may use obscene words or gestures. Others may say rude or inappropriate things to people. Children or teenagers with more complex tics may feel a need to smell or touch objects. Sometimes they jump or twirl around, jerk their head, or shrug their shoulders (motor tics). About 90% of people with TS have another disorder, like Attention Deficit/Hyperactivity Disorder (AD/HD) or Obsessive Compulsive Disorder (OCD) or anxiety. Some children, teenagers, and adults with TS also have depression. It may be that their problems making friends or being rejected because of their tics may make them feel depressed. It is also possible that the same brain problems may be linked to both TS and depression.

Many children with TS also have learning problems, particularly with reading, writing, and math.

New research is being done on “competing response training.” This therapy helps people with TS learn to recognize the onset of a tic and help stop it. The person learns to move their body voluntarily when they feel the urge to tic. Doing so seems to stop the unwanted movement or behavior.

What’s normal and what’s not?

Little twitches, or blinking, or winking over and over again are fairly common in children. They usually disappear as the child matures. There are some children, however, whose tics

are more severe and do not disappear over time. This group is often diagnosed with Tourette Syndrome. They may also deliberately injure themselves and may have difficulties with impulse control, antisocial behavior, aggression, and sleep disturbances.

What causes Tourette Syndrome?

The cause is not known. There may be some interaction between genes and the environment that leads to brain malfunctioning. The areas of the brain affected are those that have to do with movement and the control of behavior. The tics can be made worse by fatigue or stress, or even by talking about the tics or seeing someone else with tics.

How common is it?

About 1% of young people have TS. The rates are higher in people with an intellectual disability and in people with Autism Spectrum Disorder.

The diagnosis of TS is often delayed because the tics are not recognized as symptoms of a disorder. They are thought to be unimportant or just a part of growing up. Sometimes the families of children with undiagnosed TS recognize the symptoms once they read about them or hear about them from other people. They can then get their children proper diagnosis and treatment.

How long does it last?

Tourette Syndrome is usually lifelong. The average age when the symptoms begin is 7, but it can start as early as age 2 or as late as age 21. The tics seem to be at their worst during adolescence and then slowly resolve over time. Although in most children and adolescents tic-related symptoms tend to subside by early adulthood, about 10% of children with TS get progressively worse and become more disabled as they enter adulthood. Children who develop TS at a young age are more likely to have more severe symptoms.

What treatment is effective?

Treatment can improve the symptoms of TS but cannot cure the condition. Most tics don’t cause problems in everyday life but in some children, the tics interfere with their ability to learn and make friends. For this group, doctors can prescribe

medications to suppress the tics, such as haloperidol, risperidone, and pimozide. Clonidine is also being tested in TS. Some patients need to discontinue these medicines because of their side effects, though. For those who can't or do not wish to take medication, a special kind of cognitive behavioural therapy (CBT) has been shown to be effective. Talk therapy can also help people learn to cope with their TS symptoms.

No one medication seems to help everybody with TS and no treatment is completely effective for severe tics. Comprehensive diagnosis and treatment is important, so that any other conditions like ADHD, OCD, sleep disorders, anxiety or depression that are often seen in people with TS can be identified and treated, too.

BACKGROUND INFORMATION

Tourette Syndrome by Mary Robertson.
Oxford University Press, 2008; ISBN-13: 978-0199298198

Tics and Tourette Syndrome: A Handbook for Parents and Professionals by Uttom Chowdhury.
Jessica Kingsley; 2004; ISBN-13: 978-1843102038

Don't Think About Monkeys. Extraordinary Stories Written by People with Tourette Syndrome by Adam Ward Seligman.
Hope Press; 1992; ISBN-13: 978-1878267337

STEP-BY-STEP GUIDES

Managing Tourette Syndrome: A Behavioral Intervention Workbook, Parent Workbook by Douglas W. Woods.
Oxford University Press, 2008; ISBN-13: 978-0195341294

Children with Tourette Syndrome: A Parents' Guide by Tracy Lynne Marsh.
Woodbine House; 2007; ISBN-13: 978-1890627362

Coping with Tourette Syndrome: A Workbook for Kids With Tic Disorders by Sandra Buffolano.
Instant Help Books, 2008; ISBN-13: 978-1572246324

BOOKS FOR YOUNG PEOPLE

Reading Level : Ages 9-12

Tic Talk: Living with Tourette Syndrome: A 9-Year-Old Boy's Story in His Own Words by Dylan Peters.
Little Five Star; 2009; ISBN-13: 978-1589851627

Reading level: Ages 4-8

I Can't Stop!: A Story about Tourette's Syndrome by Holly L. Niner
Albert Whitman & Company, 2005; ISBN-13: 978-0807536209

Taking Tourette Syndrome to School by Tira Krueger
JayJo Books 2002 ISBN-13: 978-1891383120

WEB SITES

Tourette Syndrome Foundation of Canada
Dedicated to helping individuals with TS and their families by distributing information, promoting local self-help and professional services, and promoting understanding through education.

www.tourette.ca

Tourette Syndrome Fact Sheet from the National Institute of Neurological Disorders and Stroke.

www.ninds.nih.gov/disorders/tourette/detail_tourette.htm

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