



*Canadian Psychiatric  
Research Foundation*

# When Something's Wrong O

*Ideas for Families*



Tourette  
Syndrome  
(TS)

# Tourette Syndrome (TS)

## Tourette Syndrome (TS)

Tourette Syndrome is a brain disorder characterized by tics. Tics are involuntary, sudden, rapid muscle movements or vocalizations that recur at irregular intervals. Tics range in severity from mild to more exaggerated movements and sounds and tend to increase with stress or excitement.

Although people with TS can often suppress their symptoms to some extent, tics are not the same as habits. Children have complete control over habits, but they do not over tics. Therefore, children with TS can be misunderstood because of the complexity of symptoms; parents, friends and teachers may find it hard to believe that TS behaviours cannot be completely controlled.

TS usually appears in childhood around the age of seven. It is estimated to affect one per cent of the population and is four times more common in boys than girls. The most common first symptoms are facial tics, such as rapid blinking or mouth twitching. In some cases, involuntary sounds such as throat clearing and sniffing may be the initial sign; in others, motor (i.e., movement) and vocal tics can appear at the same time.

Generally inherited, it is thought that TS may result from the interaction of several genes with environmental or other factors.

Many children with the syndrome have associated problems, such as obsessive compulsive disorder or attention-deficit/hyperactivity disorder, described in *Anxiety and Anxiety Disorders* and *Impulse Control Disorders* in this handbook.

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## Behaviour Characteristics

- Tics – involuntary movements or vocalizations ranging in complexity from blinking, facial twitching, head or body jerking, shoulder shrugging, throat clearing, sniffing, tongue clicking, yelping, to jumping, twirling, bending, touching others; and, rarely, hitting or biting oneself, uttering ordinary words or phrases out of context or, even more rarely, explosively vocalizing socially unacceptable words
- Fatigue, along with sleepiness or irritability and hyperactivity, caused by sleep disturbances
- Learning problems related to organization and/or eye-hand coordination difficulties with handwriting and written math work; generally, difficulties with expressing thoughts in written form
- Behaviour problems resulting from poor self-esteem and/or school performance due to TS symptoms or, in some cases, from obsessive compulsive, attention deficit or impulse control difficulties

## Coping Strategies

- **Early intervention** is key to managing the disorder and preventing further disability.
- **Get help** from a qualified health practitioner, including a professional diagnosis. An accurate diagnosis will help to prevent any incorrect “labeling” of your child by others.
- **Obtain** a second opinion if possible.
- **Find** a support group for both you and your child, and exchange strategies.
- **Learn** all you can about the disorder and educate your family and your child about the disorder.
- **Don’t compare** your child to siblings or other children. Treat your child as a unique individual.
- **Re-evaluate** and modify strategies as necessary. Work closely with your child’s teacher, doctor, and school team.
- **See *Managing Problem Behaviour in Children, Working with Your Health Practitioner, and Resources*** in this handbook for more information.
- Work with a professional to manage this syndrome.
- Recognize that TS does not affect intelligence.
- Emphasize to your child that TS is not the most

## Coping Strategies

important thing about him/her. He/she is valued and loved.

- Tics tend to increase with stress, and decrease when a child is involved in an absorbing activity. Keep these points in mind when working with your child.
- Talk with your child about what is usual behaviour for his/her age and then about behaviour that is due to TS. Doing so will help give your child a context and will help him/her to reach goals of more normal, age-appropriate behaviour.
- Try to be flexible. Your child will have different needs and abilities at different times and may even go in cycles throughout a day.
- Work with your child's teachers, family, and friends to create a reassuring daily routine with a structure your child can manage and expect. Arrange extra help where necessary and take advantage of special education resources.
- Break down tasks into manageable chunks and give clear instructions about how to complete them. Allow your child to go at his/her own pace, since tics may slow down tasks.

## Coping Strategies

- Praise progress rather than criticize disorganization.
- If you are asking your child to do something, make sure he/she is ready and feeling safe in his/her environment.
- Look for activities that your child is good at, and then provide him/her with lots of praise to boost self-esteem.
- Remember, tics are not the same as habits. Your child does not have complete control over the tics.
- Ignore tics as much as you can, but don't allow them to be excuses for other behaviours that should have consequences for your child. Work with your child to understand the difference.
- Provide support and supervision, especially in unstructured environments that are less clear for your child.
- Modify the environment where you can, rather than attempting to change your child.
- Be aware of depression and suicidal behaviour (see *Mood Disorders* and *Suicide* in this handbook), since children with disorders like TS are at higher risk.

## Coping Strategies

- Don't hold a grudge against your child for his/her behaviour.
- Have, and encourage in your child, a sense of humour.
- Children with TS often suffer the added stress of teasing, rejection, and even bullying from peers. Encourage your child to talk about the disorder with classmates, friends and family, and thereby increase acceptance of tics. If your child agrees, even a presentation to his/her class or school might help. Determine the best approach with the teacher and with your child to create awareness and understanding of your child's disorder.

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# Tourette Syndrome: Treatment and Resources

## TREATMENT

The majority of young people with Tourette Syndrome are not significantly disabled by their tics or behaviour symptoms and therefore do not require medication. However, there are medications to help control symptoms that interfere with functioning. The type and dosage of medication needed to achieve maximum relief of symptoms, with minimal side effects, varies for each child and must be determined carefully by a doctor. Other forms of treatment, such as psychotherapy, relaxation techniques or biofeedback, may help the child and his/her family cope with associated psychosocial problems and stress. Partial, and sometimes full remission can occur at any time and may be short or long-lived. Tic symptoms may stabilize and become less severe during or after adolescence.

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## RESOURCES

### **Life's a Twitch!**

(Life's a Twitch® is a Web site on Tourette Syndrome and associated disorders)

Web: [www.lifesatwitch.com](http://www.lifesatwitch.com)

### **Tourette Syndrome Foundation of Canada**

#206, 194 Jarvis Street

Toronto, ON M5B 2B7

Phone: (416) 861-8398

Toll-Free: 1-800-361-3120

Web: [www.tourette.ca](http://www.tourette.ca)

### **Tourette Syndrome Association**

42-40 Bell Boulevard, Suite 205

Bayside, NY 11361-2820

Phone: (718) 224-2999

Toll-free: 1-888-4-TOURET (486-8738)

E-mail: [ts@tsa-usa.org](mailto:ts@tsa-usa.org)

Web: [tsa-usa.org](http://tsa-usa.org)

Please also see *Resources* at the back of this handbook.

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