

# **Tourette Syndrome: A Guide for Parents**

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Tourette Syndrome (TS) is a genetic neurological disorder characterized by tics, which are involuntary, rapid, sudden movements or vocalizations that occur repeatedly in the same way. Both motor and vocal tics typically occur at some time, although not necessarily simultaneously. Tics occur many times a day nearly, every day throughout a period exceeding one year. Onset is before age 18, and symptoms usually appear at age five or six. Some aspect of TS may be present in as many as 1 in every 200 people, and boys are three or four times as likely to be afflicted than girls. There is no known cure for TS, but some medications can effectively treat its symptoms.

## **Evaluation and Diagnosis of Tourette Syndrome**

***When to refer.*** A transient or a chronic tic is a relatively common occurrence during the childhood years, affecting up to 15% of all children. The actual rate of TS is difficult to determine because many individuals have such mild symptoms that the condition is not diagnosed or is misdiagnosed. Current researchers estimate that about 3% of the population has Tourette Syndrome.

In general, you will want to seek a more comprehensive assessment, starting with your pediatrician, should you observe your child exhibiting a motor and a vocal tic, either separately or simultaneously, on and off over a period of one year. Tourette-like tics may be a symptom of other medical conditions that your pediatrician and the medical team will need to address through a comprehensive neurological assessment.

***Where to go for help.*** If you are concerned that your child may be exhibiting the symptoms of TS, the first important step is to obtain a thorough medical/neurological assessment. The Tourette Syndrome Association, Inc. (TSA) can provide a listing of specialists and clinicians in your area who have experience with this disorder (see “Resources” at the end of this handout). Once a diagnosis of TS has been confirmed, you will also want to contact TSA, which has helpful information for families of children who are newly diagnosed. TSA can also provide support and knowledge about the most recent research findings, treatment approaches, and educational expertise, and connect you with local TSA chapters or support groups.

***Sharing information about the diagnosis.*** It is imperative that people in your child’s life have accurate information about TS in order to understand and to accept him or her. Socially and emotionally, it is important to note that when parents are open about their child’s needs, they can create opportunities to develop a sense of competency as an advocate. The better equipped the parents, the better equipped the child will be in learning how to accept himself or herself and how to educate others as part of becoming his or her very own, best advocate.

## **How the School Can Support Children With TS**

One of the main issues for your child at school may be the distractions of the TS ticcing. For many children, a great deal of energy is required as the child attempts to suppress the tics. The suppression of the urge to tic is similar to holding back a sneeze or tolerating an itch without scratching. As a result, it may be difficult for your child to concentrate on the work at school. It is very important to inform the classroom teacher, principal, and school support staff (school psychologists, social worker, nurse, counselor) of your child’s diagnosis. Many children who struggle with TS benefit from the following supports:

Planned *release times* (private and quiet time to release ticcing urges)

Exercise such as swimming or running

Social skills training with a focus on conflict resolution

Friendship groups

Testing and assignment accommodations available through special education or Section 504 plans for students with disabilities

The TSA, special education personnel, and community professionals can provide information to help classroom teachers support and accommodate students with Tourette Syndrome.

### **How Parents Can Support Their Children and Plan for the Future**

***Validate your child's personal strengths.*** By focusing on your child's many strengths, you will re-affirm and reinforce an emotional foundation for a healthy self-concept. For example, look your child straight in the eyes, and hold his or her face – especially when he or she is experiencing the need to release a facial tic or grimace. Verbally state that you are *very* proud of your child, and then state a specific, concrete personal strength, such as great love for soccer, taking excellent care of a pet hamster, or his or her wonderful skills in painting or pottery.

***Intervene and advocate upon request from your child.*** If your child is struggling with peer conflicts, ask your child what specific things he or she would like to address. At times, your son or daughter will wish to keep issues private, and he or she may request that you let him or her resolve specific peer conflicts. If the situation becomes too overwhelming, ask your child if a classroom educational talk or video would be a good idea. Encourage your child to develop self advocacy skills early on.

***Recognize that, for your child, release is a good thing.*** Talk about what, when, and how your child needs to release physical tensions, repetitive thoughts, or energy. For many kids as well as adults, helpful physical release times include any aerobic exercise such as swimming, biking, walking, running, etc. If *corprolalia* or *corpropraxia* (obscene vocalizations or gestures) is a stressor, specify with your child that he or she can release in a specific place, or if possible, time. Accommodations such as preferential seating, near the classroom door, is helpful; as well as, devising a non-verbal and non-intrusive clue between the child and the teacher, which signals that the child may go to a pre-agreed upon designated room to release. This accommodation is also helpful for students in general, who need some release time.

***Talk openly about every aspect of TS and how this feels to your child.*** Let your child express himself or herself openly with you. If he or she wishes, encourage your child to write poetry, or do art work about how it feels inside to experience the need to tic and release that tension. Talk with your child to help identify the type of tics that he or she may be experiencing this week or this month. For some families whose children may be taking medication(s) for other needs, it is a good idea to keep a medication and tic log with dates and observations. This information is very helpful as your child's tics wax and wane. At times, tic management is challenging for families due to the intermittent increase and decrease of TS and any co-occurring psychiatric needs such as Obsessive Compulsive Disorder, ADHD, or a form of depression.

***Understand and recognize that TS is only one aspect of who your child is as a person.*** At first, a child, as well as the family, may experience fear and embarrassment about his or her ticcing. Help your child recognize how much you value him or her as a member of your family, and give your child time to adjust to the changes that are occurring inside of his or her body. Specifically, hold your child, touch the area on his or her body that he or she is experiencing a tic, and reassure your child that it is good to release that tension. Then, give your child a hug and let your son or daughter know how much you love him or her.

**Educate your son's or daughter's siblings, other relatives, friends, classroom teachers, colleagues, and your community about the many aspects of TS.** For example, provide a TSA brochure for your child's school cumulative record file, district health file, and the classroom teacher's working file. Ask to place some TSA information pamphlets or brochures at your local church, soccer league, or doctor's office. Also, provide newsletters and other materials that are written for kids who struggle with TS, such as the *TSA That Darned Tic* kids' newsletter or videos (see "Resources" at the end of this handout).

### **Summary**

Most of all, your son or daughter, right now, needs your *reassurance* and *unconditional love*. Parents of children with TS often feel that the future seems more uncertain and unpredictable. Accurate information available from journals, newsletters, websites, and the wealth of resources available from TSA and other resources can provide some answers, as well as comfort.

In general, remember to nurture and protect your child's sense of self-worth, place fair expectations upon him or her, and remember to continually remind your child how much you love him or her, unconditionally. As parents and educators, we need to embrace our children for all that they are and for all that they can become.

### **Resources**

Haerle, T. (2003). *Children with Tourette Syndrome: A parent's guide*. Bethesda, MD: Woodbine House.

Waltz, M. (2001). *Tourette's Syndrome: Finding answers and getting help*. Sebastopol CA: O'Reilly.

Wilens, T. E. (2003). *Straight talk about psychiatric medications for kids*. New York: Guilford.

### **Websites and Organizations**

Connecticut TSA, Clinical Information page—[www.tsact.org](http://www.tsact.org)

*Latitudes* (newsletter), subscriptions: Association for Comprehensive NeuroTherapy, 1120 Royal Palm Beach, Boulevard #283, Royal Palm Beach, FL 33411. Telephone: (407) 798-0472; [www.latitudes.org](http://www.latitudes.org)

*That Darn Tic: A Newsletter by and for Kids with TS*: TSA, 42-40 Bell Boulevard, Bayside, NY 11361. [Peggy Harford, editor: [peggy.harford@tsa-usa.org](mailto:peggy.harford@tsa-usa.org)]

Tourette Syndrome Association, Inc.: 42-40 Bell Boulevard, Bayside, NY 11361-2820; (718) 224-2999; [www.tsa-usa.org](http://www.tsa-usa.org) [see Catalog of Publications and Videos]

*Rhonda Palmquist, MSEd, was a school psychologist in Yakima, WA at the time she wrote this handout, and the parent of an eleven-year-old son with Tourette Syndrome (who reviewed this handout and offered valuable suggestions). She is also a parent volunteer with the Washington TSA. This handout is reprinted from NASP's Helping Children at Home and School: Handouts for Families and Educators (2004).*

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