TOURETTE SYNDROME: A GUIDE FOR PARENTS

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Tourette Syndrome (TS) is a genetic neurological disorder characterized by tics. Tics are involuntary, rapid, sudden movements or vocalizations that occur repeatedly and in the same way. Both motor and vocal tics typically occur, although not necessarily simultaneously. Tics occur many times a day, nearly every day throughout a period exceeding 1 year. Onset of TS is before age 18, and symptoms usually appear at age 5 or 6. 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 the symptoms.

Evaluation and Diagnosis

Rate of TS. The actual rate of TS is difficult to determine because many people have such mild symptoms that the condition is not diagnosed or is misdiagnosed. Current researchers estimate that about 3% of the population has TS.

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. However, in general, should you observe your child exhibiting a motor or vocal tic, either separately or simultaneously, on and off over a period of 1 year, you will want to seek a more comprehensive assessment, starting with your pediatrician. 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. The Tourette Syndrome Association (see “Resources” at the end of this handout for the website and contact information) can provide a listing of specialists and clinicians in your area and provides support and information about the most recent research findings, treatment approaches, and educational expertise, and can connect you with local 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 your child. Socially and emotionally, when parents are open about their child’s needs, they can create opportunities leading to the development of strong advocacy skills. 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 Your Child

You need to tell your child’s teacher, the principal, and the school support staff (school psychologists, social worker, nurse, counselor) of your child’s diagnosis. The Tourette Syndrome Association, special education personnel, and community professionals can provide information to help the teacher support and accommodate your child.

One of the main issues for your child at school may be the distractions of the TS ticcing. A great deal of energy is required as your 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. Your child has to become distracted, and it may be difficult for your child to concentrate on the work at school. It has been found that many children who struggle with TS benefit from:

• 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
How You Can Support Your Child and Plan for the Future

**Confirm your child’s personal strengths.** By focusing on your child’s many strengths, you will reaffirm and reinforce an emotional foundation for a healthy self-concept. For example, look your child straight in the eyes. Hold his or her face, especially when experiencing the need to release a facial tic or grimace. Say you are very proud of what he or she has done in his or her life, and then state a specific, tangible example, such as playing soccer well or taking care of the pet or drawing well, anything in which your child can and should take great pride.

**Intervene and advocate upon request from your child.** If your child is struggling with classmates or with friends, and there is conflict with them, ask what specific things he or she will like to do about it. At times your child may wish to keep these issues private, and you should honor that, or your child may wish to resolve the specific problem alone, and you should also honor that. If the situation becomes too overwhelming, though, ask your child if a classroom talk or maybe even a video explaining TS may 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, or running. If corporalita or corporaproxia (obscene vocalizations or gestures) is a stressor, decide with your child where he or she can release in a specific place or, if possible, at a specific time. Accommodations such as preferential seating, near the classroom door, are helpful. What also is useful is devising a non-verbal and non-intrusive cue between your child and the teacher that signals that your child has to 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. Encourage your child to write poetry, for instance, or write a story 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. If your child is taking other medications than medications for TS, keep a medication and tic log with dates and observations. This information is very helpful as your child’s tics wax and wane. Tic management can be challenging for both your child and your family owing to the intermittent increase and decrease of TS and any co-occurring psychiatric needs such as Obsessive Compulsive Disorder, Attention Deficit Hyperactivity Disorder, or a form of depression.

**Understand and recognize that TS is only one aspect of who your child is as a person.** At first, your child, as well as the entire family, may experience fear and embarrassment about the ticcing. Help your child recognize how much he or she is valued 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. Hold your child. Touch the area on your child’s body that he or she is experiencing a tic, and be reassuring that it is good to release that tension. Then, give a hug and let your child know how much you love him or her.

**Educate your other children, relatives, friends, classroom teachers, colleagues, and your community about the many aspects of TS.** Provide a Tourette Syndrome Association brochure for your child’s school cumulative record file, district health file, and the teacher’s working file. Ask to place some pamphlets or brochures or newsletters or videos that are for kids at your local church or synagogue, for instance, or at the soccer league or doctor’s office, anywhere the information may be of use.

**Summary**

Your son or daughter, right now, needs your reassurance and unconditional love. It is not uncommon for parents of children with TS to often feel that the future seems uncertain and unpredictable. Accurate information available from journals, newsletters, websites, and the resources available from the Tourette Syndrome Association can provide some answers, as well as comfort.

In general, nurture and protect your child’s sense of self-worth. Place fair expectations upon your child. And remember to continually remind your child how much you love him or her. We need to embrace our children for all that they are and for all that they can become.

**Resources**


**Websites and Organizations**

Connecticut Tourette Syndrome Association, Clinical Information page—www.tsact.org

*Latitudes* (newsletter), subscriptions: Association for Comprehensive NeuroTherapy, P.O. Box 210848, Royal Palm Beach, FL 33421-0848; (561) 798-0472; www.latitudes.org

*That Darn Tic: A Newsletter by and for Kids With TS*: Tourette Syndrome Association, 42-40 Bell Boulevard, Bayside, NY 11361; Peggy Harford, editor: peggy.harford@tsa-usa.org

Tourette Syndrome Association: 42-40 Bell Boulevard, Bayside, NY 11361; (718) 224-2999; www.tsusa.org

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