# TIC DISORDERS AND TOURETTE SYNDROME

# SCHOOL CARE PLAN

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Office of Superintendent of Public Instruction

Education Support

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# Introduction

The purpose of this school care plan is to provide school district staff with information, references, and resources for identifying and assisting students with Tourette Syndrome and tic disorders so that the student can succeed in the school setting. The emphasis is on Tourette Syndrome, but the information can be applied to students with other tic disorders and associated learning disabilities. The care plan consists of a brief description of Tourette Syndrome and tic disorders, program implications for the various school problems or symptoms, and reference and resource sections. This document is intended to provide introductory information about the disorders and to direct school district staff toward resources for developing individual student care plans and educational programs.

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# TIC DISORDERS AND TOURETTE SYNDROME

# SCHOOL CARE PLAN

## Description and Incidence

Gilles de la Tourette Syndrome (TS) is one of a number of tic disorders usually first diagnosed in infancy, childhood, or adolescence. "The Tic Disorders can be distinguished from one another based on duration and variety of tics and age at onset. Transient Tic Disorder includes motor and/or vocal tics lasting for at least 4 weeks but for no longer than 12 consecutive months. Tourette's Disorder and Chronic Motor or Vocal Tic Disorder each have a duration of more than 12 months but are distinguished by the requirement for Tourette's Disorder that there be multiple motor tics and at least one vocal tic."[1] p. 101. (See Appendix 1 for diagnostic criteria.)

The estimated incidence of Tourette's ranges widely but is probably four to five individuals per 10,000. It occurs two to three times more frequently in males. Undoubtedly, there are numbers of other students with symptoms who have not been diagnosed. When diagnosed and treated early, many of the associated learning, emotional, and social disabilities it produces can be lessened or dealt with more effectively. The goal of any program for a person with Tourette Syndrome is to assist the person in learning and interacting productively in school and society.

Tourette Syndrome is a multiple tic disorder, with motor and vocal tics present, but not necessarily concurrently, which begins in childhood and is a lifelong condition that waxes and wanes in its manifestations and intensity.

Chronic Motor or Vocal Tic Disorder is characterized by either motor or vocal tics persisting for at least a year.[1] There is a wide range—from mild to severe of symptoms and disability—from child to child. In addition, a high percentage of children with tic disorders may also have learning disabilities and associated co-morbidities, such as attention deficit hyperactivity disorder (ADHD) and obsessive compulsive disorders (OCD). It is difficult to accurately assess the abilities of these students because of (1) the symptomatology of the disease, (2) the effects of medications, (3) the emotional response of the child to his/her family and environment, (4) the inability to control his/her body, and (5) the socially disabling effects of the tics.

## Diagnosis

Diagnostic criteria for Tourette Syndrome include:

1. Age of onset before the age of 18, usually between 6–7 years of age.

2. Rapid, recurrent, repetitive, purposeless, and involuntary motor movements affecting multiple groups of muscles.

3. Multiple vocal tics (grunts, barks, moans, shouting of socially inappropriate words or phrases, etc.).

4. Ability to suppress movements and sounds voluntarily for minutes to **hours.**

5. Variations in the intensity of symptoms over weeks or months.

6. A duration of symptoms for more than one year with no tic-free period of more than three months.[1]

### Symptoms/Course

Tourette Syndrome begins in childhood, usually with a single tic involving the head. The tic may be eye blinks, facial grimaces, or head tics. Tics can spread to the trunk and legs and may result in major motor activities such as hopping, jumping, and kicking. Vocal tics may occasionally be the presenting symptom. Not all patients have vocal and motor tics present at the same time though both will occur at some time during the course of the disorder. Vocal tics may include, but are not limited to, grunting, barking, snorting, humming, and coughing. A small percentage of patients develop coprolalia (involuntary cursing). Others develop echolalia (repetition of another's words or phrases), palilalia (repetition of one's own last words or phrases with increasing rapidity), echokinesis or echopraxia (imitation of the movements of others), and coprapraxia (impulsive obscene gestures). Other symptoms are touching, repetitive thoughts, and obsessive compulsive behavior.

All of these manifestations are disturbing and embarrassing to the child and disruptive of normal classroom activities. Many children with TS are misdiagnosed with behavior or psychotic disorders. In one study, the average length of time from symptom onset to diagnosis was more than 13 years.[2] Many patients have a significant decrease of symptoms and even remission in adulthood, but initially symptoms tend to worsen during periods of rapid growth such as adolescence.

### Etiology

The cause of Tourette Syndrome is unknown. The basic defect is thought to be a biochemical abnormality in the basal ganglia of the brain.

### Treatment

There are a wide range of medications available for the treatment of TS and associated comorbidities. Drugs such as pimozide (Orap) and clonidine (Catapres) are used to control tics. Antidepressants and stimulants are prescribed to improve attention deficits. Other drugs are helpful in treating depression and obsessive/ compulsive behaviors and aggression. Because of the problems associated with combining these drugs, the physician, parent, and child must often choose the most debilitating symptoms to target with medications. Even then, the use of one drug to control some troubling symptoms may exacerbate other symptoms. All medications have undesirable and often severe side effects. In addition, they must be monitored and dosage adjusted for each patient by the physician who will rely partially on parent, student, and school staff observations.

## Collaborative Problem Solving As a Model for Intervention

(Tom Delaney)

Considering the incidence of Tourette's and the unique manifestations of the syndrome in each child, expertise is hard to acquire. The typical school psychologist, teacher, counselor, or nurse may see, at best, a handful of children with Tourette's. This presents a number of problems for school staff, not the least of which is having sufficient comfort with a certain lack of knowledge to confidently make the necessary inquiries and design the appropriate interventions.

Parental knowledge of the child's unique characteristics will always be critical information. They know the child best. Outside expertise is ultimately available. The need for a model of collaborative practice and ongoing problem solving is therefore needed in these type of situations. Fortunately, though we may not consider ourselves very knowledgeable regarding the student with Tourette's Syndrome enrolling in our school, we know a good deal about collaborative problem solving as a model for intervention in the schools.

Support of the student's teachers is essential as the teacher sets the tone for acceptance of symptoms in the classroom. Other school staff such as bus drivers and playground attendants should be involved in development and implementation of the student's care plan.

Collaborative problem solving has a long history and supportive research in schools, with a strength at combining parental and outside or medical expertise and educational expertise, to constantly monitor and modify instruction. We are familiar with the sequences of the process: problem description, functional assessment, intervention planning, and continuous progress monitoring. A brief description of each step follows:

> Problem description: A brief statement of the identified problem, focusing on the discrepancy between the setting of demands and the performance of the student.
>
> Functional assessment: Practical data collection that guides intervention and helps set goals for instruction. The purpose of this is very different from the usual assessment aimed at categorical eligibility and labeling.
>
> Intervention planning: Goal setting and designing of instruction in a collaborative consultation style.
>
> Continuous progress monitoring: **Data on the success of the intervention is collected at multiple points or continuously, not just pre/post.** Data collected before and after interventions can never guide instruction. It can only tell you afterwards that things should have been done differently.

Transition planning: Can also be done within this same process. Parents are especially urged to begin planning transitions for these children early with school staff. It is not unreasonable to start the year prior to a major transition between schools, etc. The key is to establish collaborative relationships between parents and school staff, not only to have the intervention plan in place early, but to establish trusting relationships prior to a crisis.

## Nursing and Program Implications

Most children display at some developmental level repetitive movements or habits as a tension discharging activity. These types of tics (throat clearing, eye blinking, etc.) that may even become nonintentional usually disappear over time if little attention is paid to them. The school nurse or other designated school staff should be asked to report the appearance of a tic that persists in a child aged 5–15 years. If this occurs, the parents should be alerted and the child referred for evaluation to a physician knowledgeable about tic disorders. The basis of all care is understanding of the student, the disease, and its manifestations. It is also important to communicate to the student that you want to help and that you understand he/she cannot always control behavior.

Following is a chart listing specific disabilities or symptoms that may be manifested in the classroom by a student with TS. Very brief program implications are listed in the right-hand column of the chart. Appendix 2 contains a list of resources (some of which are available from the Office of Superintendent of Public Instruction [OSPI]) and an order form from the TS Association. The references from the TSA contain much more detail and recommendations for school staff providing care and education for students with TS. You are also referred to the *Attention Deficit Hyperactivity Disorders Handbook* and related information on the OSPI Web site (http://www.ospi.wednet.edu). SPI Bulletin No. 31-98 Education Support contains information on the procedures for administration of medications to students.

| **Disability/Symptom** | **Program Implications** |
|---|---|
| Severe handwriting problems—difficulty with sustained handwriting | Utilize tape recorder, peer scribe, oral reports, keyboarding, computer programs and programs to improve visual-manual skills. |
| Difficulty maintaining attention and independent reading | Direct, proximate contact with teacher and directions directly from teacher. Reduce distractions; break up independent work into small, discrete sections.[3] |
| Difficulty in testing situation | Give oral tests when possible; increase time for test taking by 1.5 times. May be necessary to take privately so as not to disturb other students. See TSA publication *Helpful Techniques to Aid the TS Student.* |
| Learning disorders | Evaluate each child carefully for associated learning disabilities and provide appropriate accommodations for identified needs. |

| **Disability/Symptom** | **Program Implications** |
|---|---|
| Discipline issues | Consult with professional school staff (e.g., psychologist, counselor, nurses) to assist parents and teachers to establish and maintain a consistent behavioral management plan for both school and home, set reasonable expectations, understand that the tics worsen under stress and that punishment for tics is not appropriate. Consequences for inappropriate behavior are appropriate. |
| Motor tics/vocal tics | May be offensive and disruptive. Provide for private expression of tics; consider safety issues in all classes including those using dangerous chemicals or tools. Explain student's inability to control actions to classmates **if** student and parents approve. |
| Fatigue | Be aware of fatigue with repetitive large muscle tics and attempts to suppress tics. Frequent large muscle tics may also increase caloric needs, and snacks may be necessary between meals. May need to decrease homework. |
| Medications and side effects | Give medications according to orders and secure parent and physician permission (see SPI Bulletin No. 31-98 for conditions of giving oral medications in schools[4]), monitor student for drug side effects and for drug effectiveness, secure detailed drug information and educate teachers on side effects and effectiveness. Be aware of effects of medication such as possible cognitive dulling and fatigue. Be aware of school phobia from medication and discuss with parents and physician. Inform physician so that medication and/or dosage may be changed. |
| Actual and perceived isolation from peers | Refer student to school counselor/psychologist/nurse to counsel student and peers for acceptance, **increase self-esteem,** praise for even minor accomplishments, encourage student to talk about feelings on 1:1 or in groups of others with Tourette's, show films from Tourette Syndrome Association (see resources, p. 11), help student develop coping strategies, encourage participation in group activities. |
| Compulsive behaviors that impair school work | Consider small-group instruction with individualized attention or resource room. |
| Short temper and argumentative | Provide opportunity for physical movement; encourage relaxation and body control techniques as well as movement education to increase body control. Provide explanations to parents, peers, and staff. |

| **Disability/Symptom** | **Program Implications** |
|---|---|
| Explosive anger/distinct episodes of intense anger or rage not typical of student’s usual demeanor. | Ensure the safety of the student, other students, and staff. Structure, direction, and limits in the expression of the episode must be developed with parents, physician and student.[5, 6] The responsible adult, usually the teacher, must apply appropriate intervention techniques. Frequent reevaluations of the plan may be necessary. |
| Cognitive dulling, lethargy, seeming lack of interest, decrease in coordination | Could be due to medication and/or depression. If worsening or severe, report to parents for physician reevaluation; allow extra time and attention for tutoring, studying, and testing. |
| Stress increases tics | Teach coping skills to handle stress; may need to avoid competition. Intensive involvement in enjoyable activities (sports, music) decreases tics and stress and calms. |
| Mental tics (need to silently repeat words, numbers, phrases) | Allow extra time to complete responses, assignments, and to refocus attention; provide a structured school environment with minimal distraction. |
| Waxing and waning of symptoms of comorbidities and tics | Explain to parents, peers, teachers that student has very limited control and that expression of tics and other symptoms are involuntary as well as ever-changing and coming and going. |
| Changes in behavior patterns. | Inform teachers of need to report behavior changes, side effects of medications, frequency and intensity of symptoms. Ensure frequent contact between nurse, parents, teacher to maintain consistent behavior management. |
| Obsessive/compulsive disorder (OCD) | Refer to psychologist and/or M.D. to assess and explore the student’s obsessions and compulsions. Include the student in planning accommodations (i.e., replacing negative obsession with positive ones) and determining how much information is shared with staff and classmates.<br>Develop a plan to accommodate the obsessions/compulsions that interfere with the educational program. Discuss with parent and M.D. the possibility of medication to decrease this symptom. |

## Conclusion

Students with tic disorders, Tourette Syndrome, and a range of associated behavioral disorders and learning disabilities present many challenges to school staff. This school care plan provides staff with current information and resources to assist in the development and the provision of a safe, nurturing, and therapeutic school environment.

# ENDNOTES AND BIBLIOGRAPHY

## Endnotes

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2. Shapiro A.K., Shapiro E., Bruun R.D., Sweet R.D.: Gilles de la Tourette Syndrome. New York, Raven Press, 1978.

3. Attention Deficit Hyperactivity Disorders Handbook, OSPI, March 1994.

4. Bulletin No. 31-98, Education Support, The Administration of Medications in Schools, OSPI, April 24, 1998.

5. Tourette Syndrome and Repeated Anger-Generated Episodes, Cathy Buckman, M.D., Ruth D. Braun, M.D., Tourette Syndrome Association publication.

6. Discipline and the TS Child, A Guide for Parents and Teachers of Children with TS, Ramona Fisher-Collins, M.Ed., TSA publication.

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# Appendix 1

Appendix 1 has been deleted from the download file due to copyright constraints

# Appendix 2

## RESOURCES

1. Washington State Chapter of the Tourette Syndrome Association, c/o Roseanne Torgerson, President, 409 18th Avenue East, Seattle, WA 98112, (206) 322-4754.

2. Tourette Syndrome Association, Inc., 42-40 Bell Blvd., Bayside, NY 11361, (718) 224-2999, see attached listing of publications. http://tsa.mgh.harvard.edu

4. Brien W. Vlcek, M.D., attending neurologist, Pediatric Neurology Clinic, CHMC, (206) 223-5501.

5. Lee Adelman, R.N., B.S.N., B.A., Clinical Nurse Specialist, Pediatric Neurology Clinic, CHMC.

## Videos*

1. Stop it! I Can't. A VCR tape for elementary school ages (13 min.).

2. Inservice Film for Educators: A Regular Kid, That's Me. Depicts students aged 7–17 and TS in classroom setting. Includes information and management strategies. 45 min.

3. Tourette Syndrome: A Guide to Diagnosis of TS. Diagnostic tool for professionals developed for inservice presentations. 30 min.

4. Tourette Syndrome: The Sudden Intruder. A general interest VCR tape (30 min.) available on loan from OSPI. Call (360) 753-2744 to schedule.

* All videos are available on loan to school staff from OSPI. Call (360) 753-2744 to schedule.