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What a Difference a School Nurse Makes!

A Tourette Syndrome Guide for School Nurses

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Presentation Outline

- Welcome
- Tourette Syndrome Overview
- Challenges faced by TS students
- What a Difference a School Nurse Makes! LEAD
- Strategies and tips for families and schools

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OVERVIEW OF TOURETTE SYNDROME AND ASSOCIATED CONDITIONS

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Tourette Syndrome (TS) Overview

- Tourette Syndrome is a neurological disorder characterized by tics
- Tics are sudden, rapid, recurrent, non-rhythmic, repetitive *motor movements* or *vocalizations*
- Tics are involuntary
- Two categories of Tics:
  - Motor: movements
  - Vocal (phonic): sounds

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TS Overview: Tics

- Tics may be ***simple*** or ***complex***
- Simple Tics: Involve only a few muscles or simple sounds
- Complex Tics: Involve multiple groups of muscles

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TS Overview: Diagnostic Categories

- **Tic Disorders – DSM-V**
  - Tourette Disorder
    - Duration of more than 12 months, **both** multiple
    - motor tics, and at least one vocal tic present during
    - illness, although not necessarily concurrently, tics
    - throughout day, nearly every day, onset before 18
  - Persistent (Chronic) Motor or Vocal Tic Disorder
    - Duration of more than 12 months, Either motor tics or
    - vocal tics, **but not both**, have been present, onset
    - before18
  - Provisional Tic Disorder
    - Motor and/or vocal tic lasting 4 weeks but not longer
    - than 12 months

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TS Overview: Motor Tics

	Examples of Motor Tics		
Simple	(Sudden, brief, meaningless movements)		
	Eye blinking Eye movements Facial grimacing Nose twitching Mouth movements Lip pouting, lip licking Head jerks, head shakes	Arm extending Lip-licking Rolling eyes Squinting Abdominal tensing Kicks Finger movements	Shoulder shrugs Brushing Arm jerks Leg jerks Tapping Jaw snaps Tooth clicking
Complex	(Slower, longer, more, purposeful movements)		
	Facial gestures Pulling at clothes Touching people, objects, self Smelling fingers, objects Jumping or skipping Sustained looks	throwing Poking Thrusting arms, body Biting Gyrating and bending Self injurious behaviors: hitting, biting, pick skin	Banging Posture changes Gestures with arms Copropraxia (obscene gestures) Sexually touching self, others

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TS Overview: Vocal Tics

	Examples of Vocal (Phonic) Tics		
Simple	(Sudden, meaningless sounds or noises)		
	Throat clearing Coughing Sniffling Spitting Screeching Barking Grunting	Gurgling Clacking Hissing Sucking Snorting Squeaking Humming	Whistling Yelling Screaming
Complex	(Sudden, more meaningful utterances)		
	Syllables Words Phrases Statements ("Shut up," "Stop that," "Okay honey" Animal-like sounds	Speech atypicalities: changes in tone, intensity, accents, rhythm, pitch Stuttering	Coprolalia (obscenities, socially taboo phrases) Echo phenomena: - Echolalia (repeating others) -Palilalia (repeating self)

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TS Overview: Tic Characteristics

- Tics are generally experienced as irresistible
- Tics wax can wane naturally over time
- Type, number, and frequency of tics change/vary over time and context
- Tics are often exacerbated by fatigue, illness, stress, excitement or environmental factors

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TS Overview: Tic Characteristics

- Individuals can usually anticipate tics
- Premonitory sensory urges generally precede tics
  - A sensation occurring in muscles expressing the tic
  - Described as a tension that is relieved (temporarily) by performing tic
- Like having an itch to scratch or having to sneeze

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TS Overview: Tic Characteristics

- Tics described as being between "voluntary" and "involuntary"
  - Can hold back somewhat but not resist in long term
- Tics can usually be suppressed for short periods of time
  - This often requires much energy and is distracting
  - Tension builds and ultimately becomes unbearable
    - TS children often have a burst of activity when they get home from school or go to a safe place like the nurse or counselor's office

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TS Overview: Characteristics

- Can range from mild tics to very severe: Most Mild
- Media sensationalizes:
  - Typically see most severe motor tics, rage behaviors, and coprolalia
    - Coprolalia: around 12% of TS children
      - Do not need Coprolalia to have TS diagnosis
- During sleep tics generally decrease
  - Can wake up children and be related to sleep disturbances (school tardiness, tiredness)

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TS Overview: Etiology

- Unknown cause
- Neurobiological in nature
  - Brain areas: similar to OCD and ADHD
  - Genetic link- runs in families
- Prenatal factors, PANDAS
- Influenced by Environmental Variables

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TS Overview: Epidemiology

- Lifetime prevalence of .5 to .1% of general population
- Estimated that 100,000 people have TS
- Gender: Males 3 to 4 times more likely
- 1 out of every 100 school aged children have some form of tic disorder
- Widely reported in diverse ethnic and racial groups

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TS Overview: Course

- Onset usually between ages of 5-10, mean onset 6 to 7 years.
  - Tend to be the most severe between ages 9-11
  - Childhood tic severity does not predict adulthood outcomes
- Typically begins with simple motor tic: Eye blink
- Tics begin to occur more frequently after onset
- **Tics wax and wane over time**
- Tics typically diminish during adolescence
  - Severe tics in late adolescence somewhat predictive of adult tic severity
  - Tics could diminish in adulthood but no guarantee

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TS Overview: Diagnosis & Treatment

- Diagnosis
  - Physical/ Neuro exam, Rule out other conditions
- Medical Treatment:
  - **Medication has been standard treatment**
  - Not one "anti tic" med (Anti-hypertensive, neuroleptics are common)
  - Can reduce tics substantially, but not cure
  - Side effects can be worse than tics (irritability, drowsiness, weight gain, agitation)
  - Children often try out many medications
- Non Medical Treatment
  - Behavioral Treatment - Habit Reversal CBIT
  - Relaxation, functional behavioral plan
  - Traditional Psychological Treatment
    - Education, coping strategies, social skills, monitoring

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TS Overview: Diagnosis & Treatment

- Treatment often addresses co-occurring conditions along with tics
- **Key for diagnosis and treatment:**
  - Refer to doctors who specialize in TS (neurologists,
  - psychiatrists, psychologists, NJCTS has referrals)
- **Alternative treatments**
  - Most have anecdotal or limited clinical evidence of effectiveness currently
    - Important for nurses to know because families might be using or trying these options
  - Some examples:
    - Botox, Deep Brain Stimulation, supplements
    - Dental Appliance

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TS Overview: Diagnosis & Treatment

- BIG (TREATMENT) PICTURE…..
- TS kids often have their own combination of:
  - Coping strategies that work for them
    - (Ex. chew gum, breaks, stress ball, environmental adjustments, etc..)
  - Standard treatments (medical, psychological)
    - (Ex. Medication, habit reversal (CBIT), CBT, talk therapy)
  - Educational accommodations
  - Helpful activities and alternative treatments
    - (Ex. Sports, music, art, yoga, supplements, diet, mindfulness)
  - ….And these may change as kids change…

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TS Overview: Diagnosis & Treatment

- Stages of Tic Identity (Hartke 2014)
  - Awareness (of tics, severity, impact etc.)
  - Acknowledgement (of tics to others)
  - Acceptance (that have tics)
  - Advocacy (for own needs)
  - Important to have a sense of where someone is

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Associated Disorders

- Often causes as much or greater amount of distress than TS
- Occurs very frequently with TS
- Most clinically referred children with TS have a co-morbid disorder
- Are often the targets of educational and psychological treatment

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Associated Disorders: Most frequently occurring

- Obsessive-Compulsive Disorder
  Rates range around 60% of TS cases
- Attention Deficit Hyperactivity Disorder
  Rates range from 21-90% of TS cases
- Non-OCD Anxiety Disorders
  Rates range around ~30 (or more)% of TS cases
- Learning Disabilities
  Rates range around ~20%-40% of TS cases

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Associated Disorders: Other Conditions

- Mood disorders
- Bipolar disorders
- Rage attacks (explosive anger, outbursts)
- ODD and Conduct Disorder
- Self-injurious behaviors
- Bedwetting
- Autism Spectrum Disorders
- Sleep disorder (can influence school attendance)
- High sensitivity to touch and other sensations
- Social skills deficits
- Speech and language disorders
- Executive function difficulties
- Personality disorders

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Challenges Faced By TS Students

- Teacher does not know student has TS
- Teacher believes student can control TS
- The school does not understand TS
- Substitute teachers
- Bullying, teasing, isolation
- Missed days of school, fear of school
- Focusing and paying attention can be difficult
- Studying, taking notes, and completing homework can be a major ordeal
- Dr. apts, medication trials and side effects

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CHALLENGES FACED BY TS STUDENTS

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Challenges Faced By TS Students

- Suppressing tics during class
- Worrying about obsessions and rituals
- Frustration and disappointment
- Behavioral outbursts: dealing with the aftermath
- Navigating the social world of school
- Dealing with physical and emotional pain

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Challenges Faced by TS Students

School Challenges

- Disrupting class
  - Is it fair to other students if disruptive?
  - Students upset, parents, fight possible?
- Using TS as excuse to get out of work?
- Student says they are doing it on purpose and it is not a tic

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SCHOOL NURSES: LEAD

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School Nurses: LEAD

- 20% of students receive some type of school mental health services
- Almost all schools have at least one staff member responsible for providing MH services
- Most Common type of MH providers were:
  1. School counselors
  2. SCHOOL NURSES
  3. School psychologists

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School Nurses: LEAD

- School Nurses and Mental Health (SAMHSA 2005)
  - Considered by most schools to be MH providers
  - The most common school staffing combination for handing mental health was:
    - *School counselor + school nurse + school psychologist*
  - Percentage of time a school nurse spends providing MH services: **Overall: 31.90%,**
    - *Elementary: 31%, Middle: 30%, High School: 37.57%*
  - High case loads, MH services tend to be more informal than traditional counseling
  - More training & research on SN's role with MH in schools

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"LEAD" TS Action Plan For School Nurses (Hartke, 2010)

- Learn
- Educate
- Accommodate
- Data collect

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"LEAD" TS Action Plan For School Nurses (Hartke, 2010)

- Learn
  - If you have students with TS and associated conditions become knowledgeable about TS
  - Keep up to date on the TS and associated conditions literature.
    - TS research is ongoing
  - Resources for learning and keeping up to date
    - Knowledgeable health care professionals
    - NJCTS, TAA
    - Professional journals

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"LEAD" TS Action Plan For School Nurses (Hartke, 2010)

- Educate
  - Educate your school community about TS
    - Including....
      - TS Students
        - Can give supportive/informed counseling
      - Parents
        - Recommend/ provide appropriate referrals when TS is suspected
        - Provide information about TS and special education
      - Teachers, other faculty and administrators
        - Provide in-service, speak individually
        - Clearly explain what TS is (neurological condition, etc.)
      - Non-TS Students
        - Peer In-service, talk to class
    - Helpful resources
      - NJCTS, TAA will provide referral information, and support for in-services

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"LEAD" TS Action Plan For School Nurses (Hartke, 2010)

- Accommodate
  - Help ensure that appropriate accommodations and strategies are:
    - Being implemented effectively, offer help, support and suggestions.
    - A safe relaxing break can go a long way
  - Check in with teachers, CST, parents, and TS student
  - Remember TS and OCD wax and wane

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"LEAD" TS Action Plan For School Nurses (Hartke, 2010)

- Data collect
  - Collect information regarding child's difficulties
    - Medication monitoring, breaks, changes in tics/behavior

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STRATEGIES AND TIPS FOR SCHOOLS AND FAMILIES

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Strategies & Tips

School Accommodations

- Some TS students may have a 504 plan or IEP (classified as Other Health Impaired)

- Some TS students have no formal plan but still require some accommodations, assistance, and a school faculty that is understanding

- IEP often recommended when:
  - LD has been identified, falling behind academically
  - When tics are frequent, forceful, and directly interfere with child' s ability to participate in classroom activities
  - When not making sufficient developmental gains in any domain
  - Deviant behaviors are present

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School Accommodations

- Tests: un-timed or time and a 1/2, given orally, taken out of regular classroom
- Set up a signal for student to be able to leave classroom to relieve tics
- Designate a safe place for student to go when they leave the classroom
- Let student leave class early to be in the hallway before everyone else
- Provide notes to students
- Could half assignments to lighten workload
- Provide student with extra set of books to keep at home
- Use ruler for scantron tests, or answers written on different paper and transferred by teacher onto answer sheet
- Para-professional

- Recognize when tics tend to worsen (usually later in the day)
- Put heavier subjects when tics are less
- Consider accommodations for written work - oral reports, shortened assignments, use of a computer, alpha-smart, tablet
- Provide a quiet place to work
- Headset or ear muffs (ADHD)
- Structured but flexible classrooms
- Break down assignments into parts
- No penalties for spelling mistakes
- Preferential seating
- Directions repeated and clarified
- Occupational Therapy

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Tips for School Personnel…

- Every student and situation is unique
- Meeting to discuss TS & other factors
  - Compromise and accommodations?
  - Use appropriate level of intervention
  - Individualized behavior plan
    - Clarify problem behaviors
    - Antecedent Strategies (Setting, environment)
    - Behavioral Teaching Strategies (Skills development)
    - Consequence Strategies (Staff response)

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Tips for Families & Schools

- **Responding to tics:**
  - Be patient (wait for them to complete tics)
  - Ignore tics
  - Focus on other behaviors/ the activity at hand
  - Don't tell them to stop
  - Use positive reinforcement
  - Listen, empathize, and support
  - Use breaks and quiet time
    - If separating student from group temporarily don't make a punishment, just a "break

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Tips for Families & Schools

- Remember many factors cause tics to change
  - (making it seem like kids are doing it on purpose)
  - Nature of tics (they naturally wax and wane)
  - Holding back tics (only for short time)
  - Environment-situation-illness (stress-excitement-stimulation) (sleep, relaxing, fatigue, illness, triggers)
  - Medication
  - Other co-occurring disorders (OCD etc.)
  - Random symptom fluctuation

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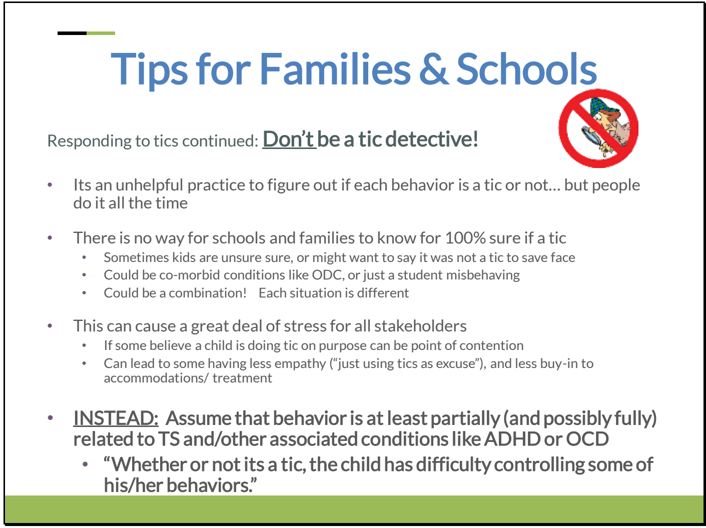

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Tips for Families & Schools

- Big picture: Symptoms wax & wane
  - (tics, ADHD, mood, OCD, anxiety etc…)
  - Freq, intensity, type, duration, triggers
- Changes in symptoms are expected
- "Anything goes"
- "Expect the unexpected"
- "Don't be a tic detective"
  - "I know they did that on purpose"
  - More on this……….

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Some Resources

- New Jersey Center for Tourette Syndrome www.njcts.org
- Tourette Association of America www.tourette.org
- Your local Tourette Association chapter
- Good video to show staff:
  - HBO I Have Tourette's But Tourette's Doesn't Have Me

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References

- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5tth ed.). Washington DC: Author.
- Attwood, T. (2007) *The Complete Guide to Asperger's Syndrome.* Philadelphia: Jessica Kingsley
- Barkley, R. A. (2006). *Attention-Deficit Hyperactivity Disorder: A handbook for diagnosis and treatment.* (3rd Ed.). New York: Guilford.
- Chowdhury, U., & Robertson, M. (2006). *Why do you do that? A book about tourette syndrome for children and young people.* Philadelphia: Jessica Kingsley.
- Conners, S. (2003). The IEP for students with Tourette Syndrome: An educator's handbook. *Tourette Syndrome Association Medical Publication.*
- Conners, S. (2003). Specific classroom strategies and techniques for students with Tourette Syndrome. *Tourette Syndrome Association Education Paper.*
- Conners, S. A., Bassuk, E., Collins, E. C., Collins, R., Favish, J., Kaplan, M., Keefe, J., Meyers, E., & Pruitt, S. K. (2005). *The educators' in-service program on understanding tourette syndrome.* Tourette Syndrome Association, Inc.
- Erenberg, G. (in press). The clinical neurology of tourette syndrome. 1-21
- Jacob, S., & Hartshorne, T. S. (2003). *Ethics and law for school psychologists* (4th ed.). Hoboken, Wiley
- Kronenberger, W.G., & Meyer, R.G. (2001). *The child clinician's handbook*. (2nd Ed.). Boston: Allyn & Bacon.

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References continued

- Leckman, J. F., & Cohen, D. J. (1999). *Tourette's syndrome: Developmental psychopathology and clinical care.* New York, Wiley.
- Lin, H., Katsovich, L., Ghebremichale, M., Findley, D. B., Grant, H., Lombroso, P.J., King, R., Zhang, H., & Leckman, J. F. (2007). Psychosocial stress predicts future symptom severities in children and adolescents with Tourette syndrome and/or obsessive-compulsive disorder. *Journal of Child Psychology and Psychiatry*, 48(2), 157-166.
- March, J. S., & Mulle, K. (1998). OCD in children and adolescents: A cognitive-behavioral treatment manual. New York: Guilford.
- Peterson, B. S., Pine, D. S., Cohen, P., & Brook, J. (2001). Prospective, Longitudinal Study of Tic, Obsessive-Compulsive, and Attention Deficit/Hyperactivity Disorders in an Epidemiological Sample. *Journal of the American Academy of Child and Adolescent Psychiatry, 40*(6), 685-695
- Wagner, A. P. (2006). *What to do when your child has obsessive-compulsive disorder: Strategies and solutions.* Lighthouse Press.
- Woods, D.W., Piacentini, J.C., & Walkup, J.T. (2007). *Treating Tourette Syndrome and Tic Disorders: A guide for practitioners* New York: Guilford.
- Zinner, S.H. (2000). Tourette Disorder. *Pediatrics in Review, 21*(11), 372-383.