Tourette Syndrome

Tourette OCD Alberta Network







Presented by Adrienne Hill



TS: Origins

Named after French physician Gilles de la Tourette

- 1857-1904
- Neurodevelopmental
- Genetic disorder
- Characterized by tics





voluntary, not purposeful

Semi-

Tics

Semivoluntary, not purposeful

Tics

Constantly change how they appear or sound









Simple Motor Tics

Involves one muscle group



Simple Motor Tics

Involves one muscle group

Movements

- Rapid Darting
- Meaningless



Simple Motor Tics	 Involves one muscle group
Movements	RapidDartingMeaningless
Simple Motor Tics	Eye blinkingNose wrinklingShrugging



Complex Motor Tics

- May Involve multiple muscle groups
- Are slower, more purposeful in appearance





Evening up

Complex Motor Tics

Tapping/banging

Touching items or self

Sustained postures of the body



Motor Tics







 \bigcirc

Simple Vocal Tics

Fast meaningless sounds





Fast meaningless sounds

Simple Vocal Tics







Complex Vocal Tics

Words, Phrases, Statements Out of context speech

X









Harmful/Painful Tics

创

Eyes rolling Causes headaches



Eyes rolling Causes headaches

> Biting Lips, arm, fingers, objects



Biting Lips, arm, fingers, objects

Eyes rolling Causes headaches Jaw snapping, rapid head twisting, jerking



- Slapping/punching self with force
- Hitting self with utensils, TV remote
- Touching/handling dangerous objects
 - Razorblades
 - Knives
 - Lit matches, cigarettes





Factors that can make symptoms worse Seeing or hearing someone ticcing

Talking about tics









Tic Suppression

People with Tourette Syndrome may try to suppress symptoms due to: Pain related to Fear of Fear of teasing embarrassment repetitive and/or bullying or humiliation movement

TS Myths

People with TS...

Always swear

Are cognitively impaired

Manifest the same symptoms all the time

Can control their symptoms if they really want to


Occurrence

Neurologist Oliver Sacks' comment regarding Tourette Syndrome incidence in 1971:

"It had an incidence, I had read, of one in a million, yet I had apparently seen three examples in an hour."

From his book, "The Man Who Mistook His Wife for a Hat"



Occurrence

- Approximately 1% of school age children
- 3 times more likely in boys than girls
- Boys and girls both have similar symptomology

Who does it affect?

All ethnic groups

• Less common in individuals of African descent

Tends to peak at age 10-12

Can continue in adulthood

• High rate of improvement in late adolescence



TS: Diagnostic Process*

- Presence of more than one motor tic and at least one vocal tic
- Tics may wax and wane in frequency, but must have persisted for more than 1 year
- Onset of symptoms before age 18
- Symptoms not due to a medical condition or substance
 - Parkinson's, Huntington's, brain trauma, medications or substances

*Diagnostic and Statistical Manual of Mental Disorders, 5th ed. (DSM-V)





Treatment Options

- Pharmacological intervention
- Cognitive behavioural interventions
 - CBIT (tics)
 - ERP (anxiety/OCD)
 - CBT (OCD, depression)

Most youth diagnosed with TS have associated disorders





Natural History of Tics and Associated Disorders

from *Tourette Syndrome* by Davide Martino and James F. Leckman

"How do you know which behaviours are TS and which aren't"

- Can be difficult to determine
- Basic rules such as not harming oneself, others or property apply to everyone.





Eye, head, neck tics make reading difficult



Eye, head, neck tics make reading difficult

Vocal tics can make class discussions and exams/quiet times difficult



Eye, head, neck tics make reading difficult

Vocal tics can make class discussions and exams/quiet times difficult

Hand, arm, body tics can make handwriting difficult



Eye, head, neck tics make reading difficult

Vocal tics can make class discussions and exams/quiet times difficult

Hand, arm, body tics can make handwriting difficult

Premonitory urge or itch can cause distraction



Areas of Impact

- Planning
- Organization
- Strategizing
- Paying attention to and recalling details
- Time management



Recognize:

- Declining academic performance
- Results in:
 - Increased anxiety
 - Frustration
 - Decreased self worth
 - Eventual refusal to engage
 - Perceived as lazy/unmotivated



Recognize:

- Every student with TS is different
- Tic expression should never be punished
- Accommodations should not be viewed as punishment
- Recognize accommodations are not a permanent fix but are support while the student learns to manage their symptoms using behavioural strategies.

Potential problems

Parents may expect that teachers know strategies

Parents/students may keep diagnosis secret

If diagnosis is shared, teachers may question diagnosis since no obvious symptoms appear in school due to suppression Fear of labels

Fear of stigmatizing

Ignore tics



Ignore tics

Let student know that they don't have to hide symptoms





Allow to leave class to relieve tics











- Reduce homework
- Extensions on due dates
- Ask student to repeat back instructions
- Help the student break larger tasks into smaller parts
- Use bullets not paragraphs
- Separate room for exams/written activities



- Redirecting when stuck
- Using non punishmentbased rewards
 - Guarantee success
- Providing written due dates/assignments online



Anticipating lost/forgotten supplies

- Having students use backpacks
 to contain all supplies
 - If backpacks not allowed
 - Textbooks/supplies in each teacher's room
 - Textbooks/supplies that student can have at home



Supporting adaptation of unacceptable tics (be creative)

- Involve classmates when appropriate
- Always involve the student
 - Spit into a cup instead of on the floor
 - Hit a box/pillow instead of a person
 - Type the insult on their phone instead of saying it to the person
 - Use words that are similar to swear words
 - Allow early release from class if hallways crowded
 - Carry something in both hands while walking in halls between classes

Help to stay on task by...

- Using short time limits with timers
 - Success must be assured
 - Gradually increase time as student improves
 - Time Timer can provide quiet visual feedback
- Providing auditory cues
 - App with tones playing at irregular intervals to remind students to be on task
 - Regularly change tone





Organizing Work/Notes

Sciences:

-1/x = -

- Use grid paper to help with organization, such as working top to bottom
- Encourage use of boxes to highlight steps

·142 =

3x - 7 = 14x + 8

Assistive technology

- Speech to text software
 - Dragon Naturally Speaking
 - Chrome Voice Recognition
- Text to speech
 - Natural Reader software
 - Audible audiobook app

Educate:

✓ All teachers

• Substitute teachers, teacher assistants

✓ Students

- Students with regular and situational contact
- ✓ Office staff
- ✓ Custodial staff
- ✓ Other parents/parent volunteers
- ✓ Bus drivers

Self Advocacy

An important skill

May not be ready or able to self advocate when symptoms are bad

Requires gentle nudging

Can take years to learn

• Help is available through to post secondary years





How the Tourette OCD Network Can Help

In class, grade specific presentations

Teacher professional development

Support for strategies in specific situations

The Tourette OCD Alberta Network

Our mission is to improve access to care for people with Tourette Syndrome and Obsessive-Compulsive Disorder province wide.

Find us at https://cumming.ucalgary.ca/resource/tourette-ocd/home

Thank you for inviting me!