Tourette Syndrome

Tourette OCD Alberta Network







Presented by Adrienne Hill

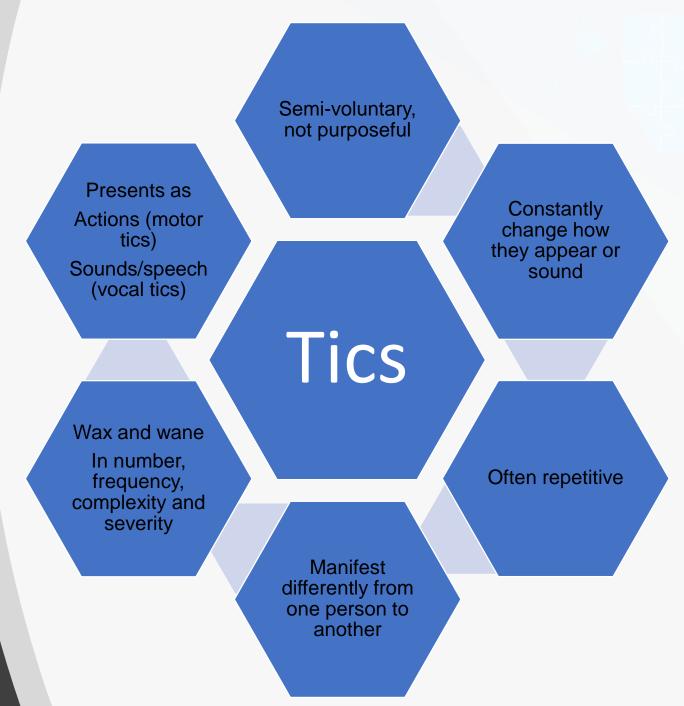
TS: Origins

Named after French physician Gilles de la Tourette

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



What are tics?





Motor and Vocal Tics

- Motor tics
- Simple
 - Eye blinking
 - Nose wrinkling
 - Shrugging
- Complex
 - Gyrating and bending
 - Multiple facial movements
 - Blink, roll eyes, open mouth

- Vocal tics
- Simple
 - Coughing
 - Throat clearing
 - Sniffing
- Complex
 - Out of context words, phrases
 - Repeating words and phrases

Coprolalia Echopraxia Echolalia Copropraxia

Potentially Embarrassing Tics Biting Lips, arm, fingers, objects

Eyes rolling

Causes

headaches

Jaw snapping, rapid head twisting, jerking

Harmful/Painful Tics





Factors that can make symptoms worse

Seeing or hearing someone ticcing

Talking about tics



What Can Help Tics?

Sleep

Exercise

Activities that require focused attention



Riding a bicycle

Playing a musical instrument

Video games



Periodic suppression is possible, but:

It takes intense effort

It diverts attention from tasks at hand

Is difficult for young children

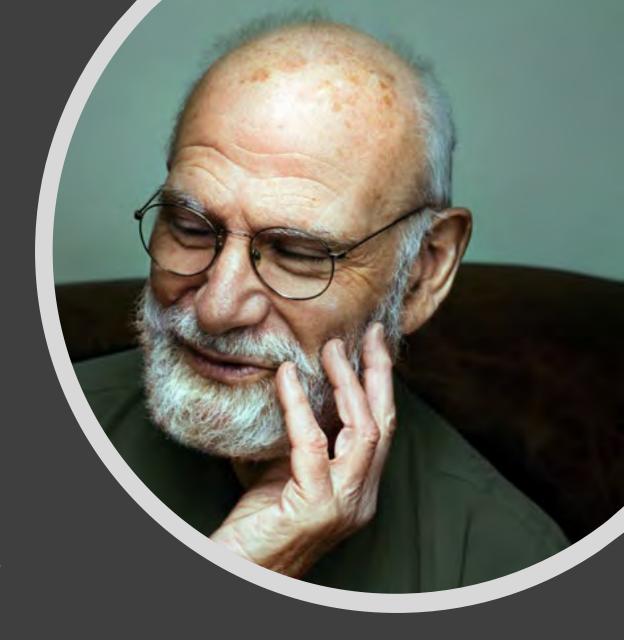


Occurrence

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"





Who does it affect?

All ethnic groups

 Less common in individuals of African descent

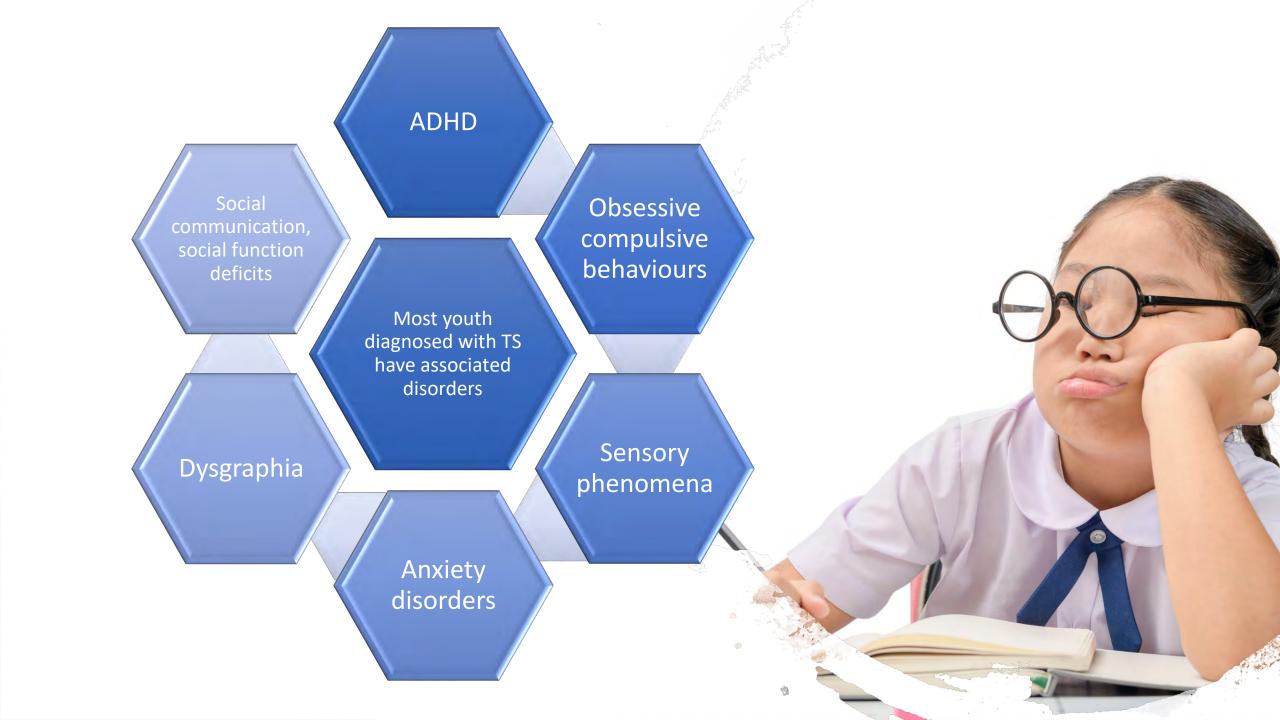
Tends to peak at age 10-12

Can continue in adulthood

• High rate of improvement in late adolescence











Compulsions

Repetitive, deliberate, ritualistic behaviours or mental acts

Performed to relieve the anxiety related to obsessive thoughts, or to prevent some negative outcome from occurring

May not be connected in a realistic way with what they are designed to neutralize or prevent

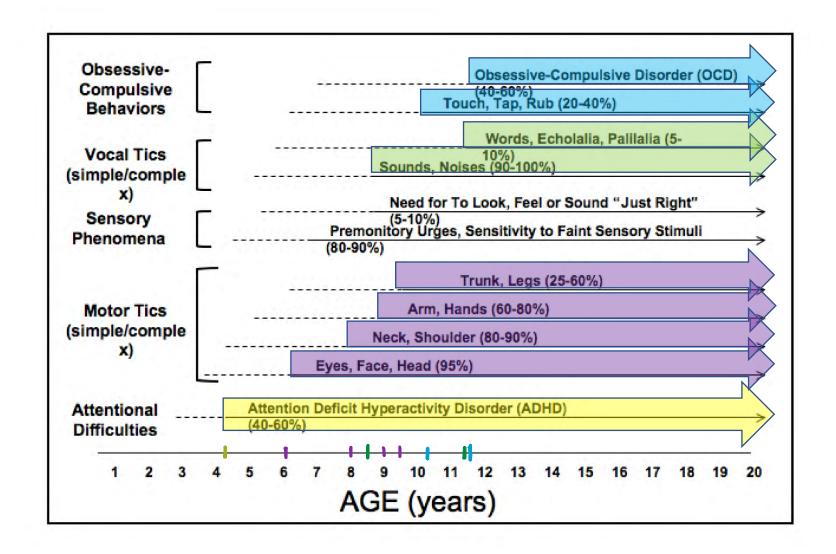


How common is OCD in children?

OCD is relatively common

1-2% lifetime prevalence

In a school population of 400 children, 6-8 are likely to have OCD



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 or OCD and which aren't"

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

For TS and OCD Educational needs vary

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No Accommodations

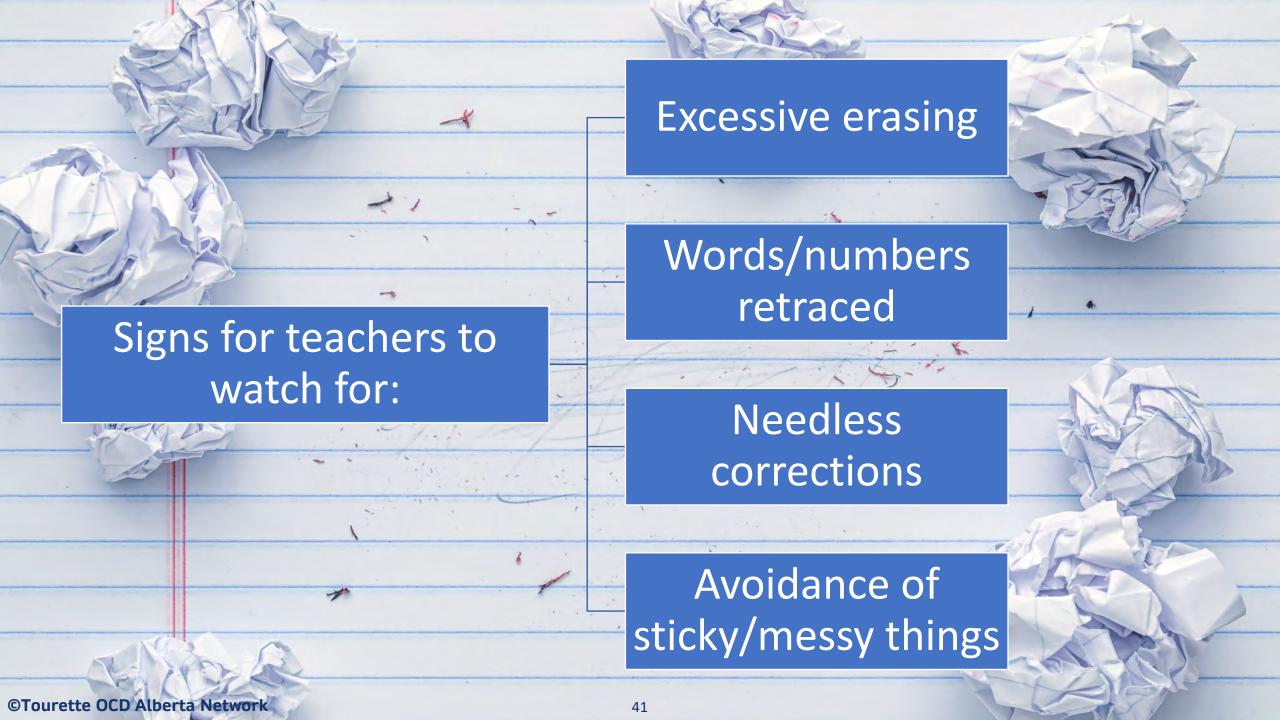
For TS and OCD Educational needs vary

No Accommodations

Requiring special educational services











Signs for teachers to watch for:

Avoiding sharp things

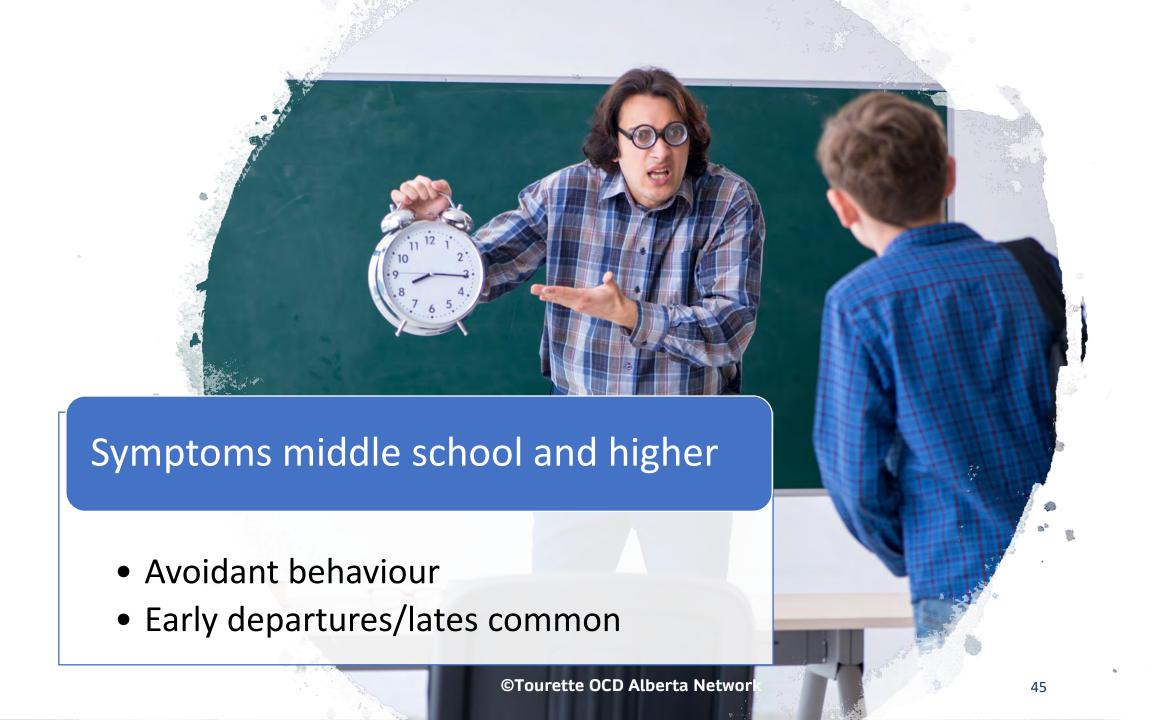
Appearing distracted/inattentive

Symptoms K-6

Perfectionistic

- Excessive writing and rewriting
- Reassurance seeking



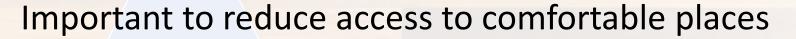






Gradually reduce passes to safe retreats

Retreats can promote avoidance



Make the uncomfortable places more comfortable eventually

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Retreats can promote avoidance

Gradually eliminate accommodations.

Recognize this will take time, sometimes years

Important to reduce access to comfortable places

Make the uncomfortable places more comfortable eventually

Gradually reduce passes to safe retreats

Retreats can promote avoidance

Gradually eliminate accommodations.

Recognize this will take time, sometimes years

Disruptive/Poor behaviour increase when accommodations withdrawn

Extra Time





Giving unlimited time can help identify issues

- OCD
- ADHD
- Learning disabilities



Extra Time

Extra time can be counter productive with OCD

- May be warranted now
- Allows for checking rituals
- Not advised in the long run











Eye, head, neck tics make reading difficult





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





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Hand, arm, body tics can make handwriting difficult





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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



Behaviour issues around homework

 Significant resistance to completing assignments



Behaviour issues around homework

• Significant resistance to completing assignments

Increase in symptoms



Behaviour issues around homework

• Significant resistance to completing assignments

Increase in symptoms

Loss of interest in preferred activities



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

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Parents/students may keep diagnosis secret Fear of labels

Fear of stigmatizing

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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



Ignore tics

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

Allow to leave class to relieve tics



Ignore tics

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

Allow to leave class to relieve tics

Electronic access to class

Students can mute during vocal tics



Ask teachers to:

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



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

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- 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





Tell teachers about us! We provide:

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!