Myths about Tourette Syndrome

1. Having TS means my child will swear uncontrollably and make a public spectacle of himself.
   WRONG!
   Less than 10% of people with TS having swearing tics in their lifetime.
   The most common tics are blinking, sniffing and throat clearing.

2. Having Tourette Syndrome means my child has subnormal intelligence and will not be able to go to university.
   WRONG!
   Having Tourette Syndrome is not associated with lower than normal IQ scores- in fact, children with Tourette Syndrome tend to have IQ scores higher than their parents.
Myths about Tourette Syndrome

3. Having Tourette Syndrome means my child has abnormal motor control and poor coordination.
WRONG!
There are surgeons, NHL players and professional soccer players with TS.

Fact

• The medical term “Tourette Syndrome” means something very different than the way this term is used by the media and non-health care workers
• Today we will try to change your perception of what this term means

What is Tourette Syndrome (TS)?

• Neurological disorder
• Named after the physician who first described it, George Giles de la Tourette
• Begins in childhood
• Defined by the presence of multiple motor and one or more vocal tics
What are tics?

- Sudden, rapid, repetitive, stereotyped sounds or movements
- Fragments of normal movements or sounds that are misplaced in context
- Simple or complex

Simple Tics

- Rapid, brief, meaningless, movements or sounds
- One muscle group involved
- Common simple motor tics
  - Eye blinking
  - Opening eyes wide
  - Nose movements
  - Shoulder shrugs
  - Abdominal tensing
- Common simple vocal tics
  - Sniffing
  - Throat clearing
  - Animal noises

Complex Tics

- Complex Motor Tics
  - Slower, may appear purposeful
  - Coordinated sequence of movements
  - Facial or body contortions
  - Jumping
- Complex Vocal Tics
  - Words, phrases or statements
  - Echolalia- repeating the words/sounds of others
  - Palilalia- repeating one’s own words or part of a word
  - Coprolalia- obscene or swear words
Is TS common?

• Yes!
• Affects 1% of the population
• Much more common in boys (3:1)

Why do I have TS?

• Hereditary
• Abnormality in dopamine signaling, a chemical messenger in the brain
• Subtle differences in brain structure seen in research studies
• Basal ganglia- part of the brain that helps control movement

When do the symptoms of TS usually start?

• Begins in childhood, usually around age 5 to 7
• By definition, symptoms must begin before age 18
• Motor tics usually occur first
  – Blinking
• Usually vocal tics follow within a year or two
  – Sniffing or throat clearing for prolonged periods after viral infections
How does the brain produce a tic?

• People with TS experience an urge to tic
  – Called a “premonitory sensation”
• Urge often described as an inner feeling of tension, or “like an itch that needs to be scratched”
• Younger children are often not able to describe this urge
• Think of the urge as a “false signal” - the brain sends a message saying there is tension or discomfort somewhere, causing the person to respond by making a movement or sound to relieve the uncomfortable feeling

Characteristics of Tics

• Tics can be suppressed
  – Children may hold in tics while at school, and release them when they get home
  – The ability to suppress tics usually improves with age
• Tics are distractible
  – Often tics are minimal when a person is mentally or physically engaged in a task that demands their attention
  – Children describe “forgetting” about their tics when they are busy

TS Symptoms

• Spectrum of severity varies considerably from person to person
• Tics may occur infrequently or be constantly present
• This can be quite variable from day to day, week to week and month to month
• Waxing and waning
• Reasons why this happens is not understood
**TS Symptoms**

- A person may have a only one or two types of tics, or many more
- Character of the tics usually evolves over time
- e.g. A child may have a shoulder shrugging tic which is present for a few weeks, which disappears, and then the child begins squeaking and head shaking for a few weeks, etc

**TS Symptoms**

- Tics are suggestible- when you talk about specific tics, people with TS feel a need to do them
- e.g. When talking about neck turning tics with a person with TS, they may feel the urge to make this movement, even if they haven’t had this specific tic for many years
- The more the person feels they MUST NOT do the tic, the greater the urge they have to do the tic

**TS Symptoms**

- May worsen with stress or excitement
- Both good and bad stress worsen tics
  - e.g. Disneyland, Christmas
TS Symptoms

- Tics tend to be more severe in childhood than adulthood for most patients
- Peak in tic severity usually occurs prior to adolescence, between age 10 and 12

Long Term Effects

- Severe tics can be socially disabling or lead to physical injury
- Many children with TS experience improvement of tics by adulthood
  - Studies suggest between 50 and 90% have a substantial reduction in tics by age 18 compared to earlier in childhood

Tics in Adulthood

- In general, tics in adults tend to change in character less
- Tend to be less emotionally distressing
- Some adults with TS experience difficulties with self-esteem and the ability to have close relationships
- Important for parents to pay close attention to self-esteem in children with TS to prevent problems in adulthood
Associated Disorders

- Attention Deficit Hyperactivity Disorder
  - Affects up to 50% of people with TS
- Obsessive Compulsive Disorder
  - Affects up to 30% of people with TS
- Difficulty expressing or coping with feelings of frustration or anger (Rage attacks)
  - Affects up to 25% of people with TS
- Usually more disabling than tics
- Important for all people with TS to be screened for these disorders

ADHD

- Three main diagnostic subtypes
  - ADHD, Combined type
  - ADHD, Predominantly inattentive type
  - ADHD, Predominantly hyperactive-impulsive type
- Symptom onset before age 7
- Impairment from symptoms present in two or more settings; social, academic or occupational

ADHD- Inattention Symptoms

- 6 or more symptoms, present for at least 6 months, to a degree that is maladaptive and inconsistent with developmental level
  - Failure to give close attention to details
  - Difficulty sustaining attention
  - Does not seem to listen when spoken to directly
  - Does not follow through on instructions
  - Has difficulty organizing tasks and activities
  - Avoids engaging in tasks that require sustained mental effort
  - Loses things required for tasks or activities
  - Easily distracted
  - Forgetful in daily activities
ADHD - Hyperactivity Symptoms

- 6 or more symptoms, present for at least 6 months, to a degree that is maladaptive and inconsistent with developmental level
  - Fidgets with hands or feet or squirms in seat
  - Leaves seat in situations in which remaining seated is expected
  - Runs or climbs excessively in inappropriate situations
  - Difficult playing or engaging in activities quietly
  - Acts as if “driven by a motor”
  - Talks excessively
  - Blurts out answers before questions have been completed
  - Difficulty waiting turn
  - Interrupts or intrudes on others

ADHD

- Symptoms of ADHD are more disabling and effect quality of life to a greater degree than the symptoms of TS
- Treatment of ADHD symptoms is the priority in children with both disorders
- Stimulant medications can be used
  - Controlled studies have shown that 80% of children with a tic disorder and ADHD will either improve or have no worsening in their tics on a stimulant medication

OCD - Obsessions

- Defined by:
  1) Recurrent and persistent thoughts, impulses, or images that are intrusive and inappropriate and that cause marked anxiety or distress
  2) The thoughts, impulses or images are not simply excessive worries about real life problems
  3) The person attempts to ignore or suppress such thoughts, impulse or images, or to neutralize them with some other thought or action
  4) The person recognizes that the obsessional thoughts, impulses or images are a product of his or her own mind
### OCD- Compulsions

- **Defined by:**
  1) Repetitive behaviours or mental acts that the person feels driven to perform in response to an obsession, or according to rules that must be applied rigidly
  2) The behaviours or mental acts are aimed at preventing or reducing distress or preventing some dreaded event or situation; however, these behaviours or mental acts either are not connected in a realistic way with what they are designed to neutralize or prevent, or are clearly excessive

### OCD

- At some point during the course of the disorder, the person has recognized that the obsessions or compulsions are excessive or unreasonable
  - **Note:** This does not apply to children
- The obsessions or compulsions cause marked distress, are time consuming (take more than 1 hour per day), or significantly interfere with the person's normal routine, occupational functioning, or usual social activities or relationships

### OCD

- **Obsessions**
  - Contamination
  - Safety or harm
  - Unwanted acts of aggression
  - Unacceptable sexual or religious thoughts
  - Need for symmetry or exactness
- **Compulsions**
  - Excessive cleaning
  - Checking behaviours
  - Ordering and arranging rituals
  - Counting
  - Repeating routine activities
  - Hoarding
OCD

• OCD may be an alternate phenotype of TS
  – In a single family, individual members may be affected with TS or OCD
• Symptoms of OCD generally begin and become more severe later in life than the symptoms of TS
• Have more of a tendency to persist in adult life
• More common in children with above average intelligence

OCD

• OCD symptoms also have a tendency to wax and wane over time like tics
• Behavioural therapy is effective for OCD symptoms; medical treatment is also available

Rage Attacks

• Inability to cope with feelings of anger and frustration
• Leads to episodes of explosive and aggressive behaviour
• Response is often out of proportion to the inciting event
• Can be extremely disabling for families
  – Having to tiptoe around explosive family member for fear of provoking rage attack
Rage Attacks

- Behavioural therapy and/or medical therapy can be helpful
- Symptoms usually improve with age and maturation

How is TS Diagnosed?

- Clinical Diagnosis
  - No tests to confirm diagnosis
  - Tests may be done to rule out other neurological diseases that only rarely cause tics (less than 1% of people with tics)
  - Based on interview with physician and physical examination

- Defining features of TS
  - Multiple motor and one or more vocal tics
  - Tics occur many times a day, nearly every day, or intermittently throughout a period of more than one year
  - The location, number, frequency, complexity, type and severity of tics changes over time
  - Onset before age 18
  - No other attributable cause
Should I be treated for TS?

• There is no cure for TS
• Treatment does not alter the course of the disorder
• Treatments help diminish the urge to tic
• Treatment can be stopped at any time (under medical supervision) for re-evaluation

Should I Be Treated for TS?

• Decision to treat tics should be based on whether or not they are causing disability
  • Are the tics interfering with enjoyment of life?
  • Are the tics painful?
  • Are the tics causing social problems? Embarrassment? Low self esteem?
  • Are the tics preventing completion of school or job related activities?
• If tics are not disabling, treatment can be deferred

What can I do to help my child with TS?

• Tics are a voluntary response to an involuntary sensation
• The urge to perform tics is not voluntary
• Do not ask your child to stop performing the tic - can make things worse!
• Be patient. Most children improve with time
• Inform teachers, close friends, relatives of diagnosis
Summary

• TS is a common, hereditary, neurological disorder
• Is benign (does not shorten life span) but can cause disability
• Frequently associated with Attention Deficit Disorder and Obsessive Compulsive Disorder
• Treatments are available if needed