

# ESSTS

European Society for the Study of Tourette Syndrome

## “Tics and Gilles de la Tourette syndrome: an introduction”

Challenges and practical guidelines for educators

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TOURETTE  
GREECE



## Tics: what are they?

- Spontaneous, repetitive, involuntary movements
- Misplaced in time / context / frequency
- Motor or vocal\*
- Simple or complex\*

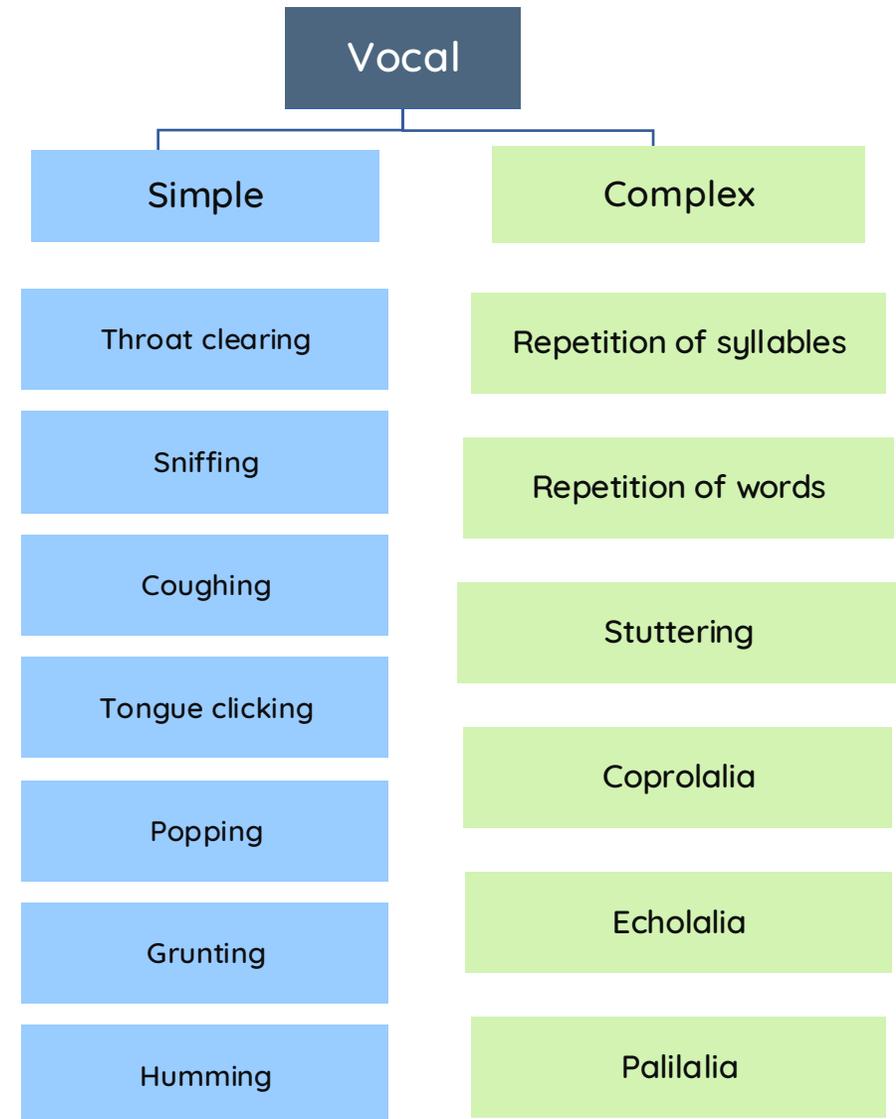
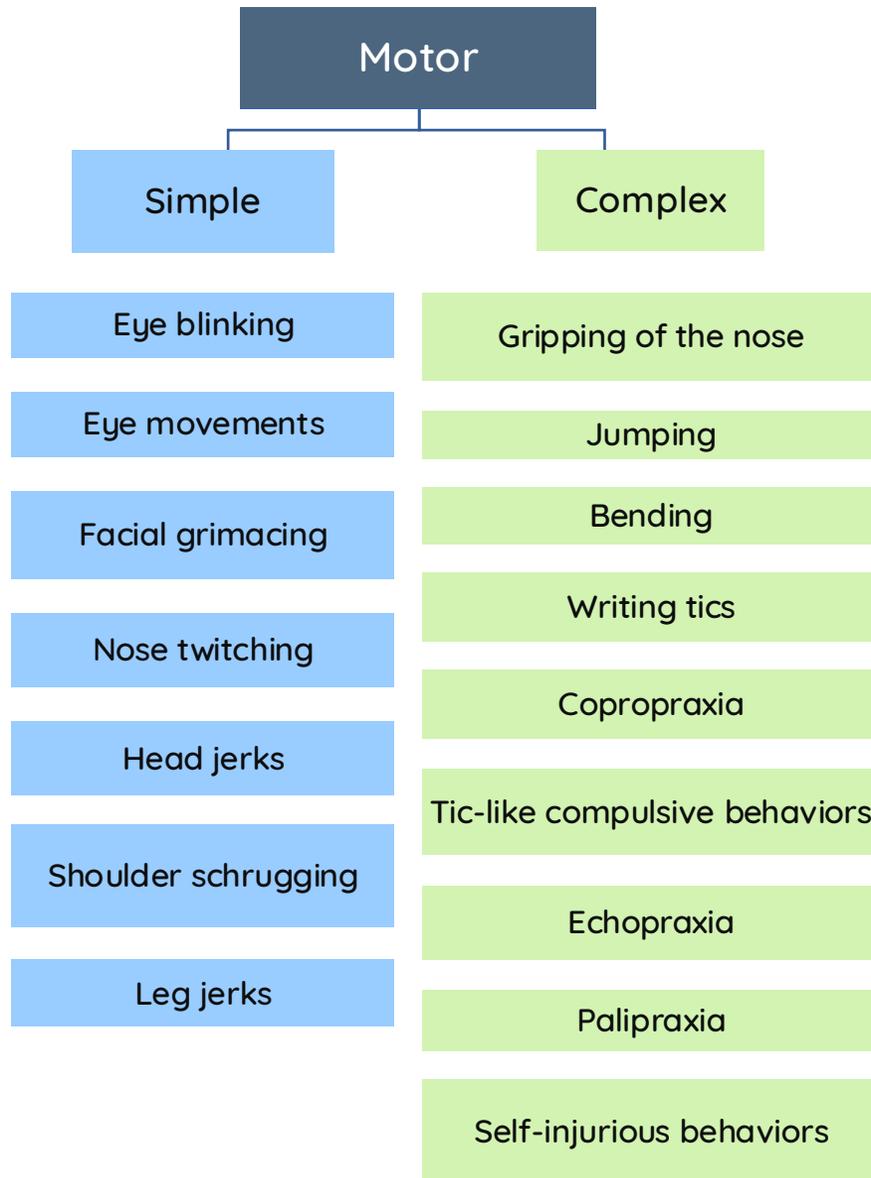


## Tics: what are they?

- Preceded by a sensation or urge to execute the tic
- Accompanied by transient relief after performing the tic
- Transiently suppressible



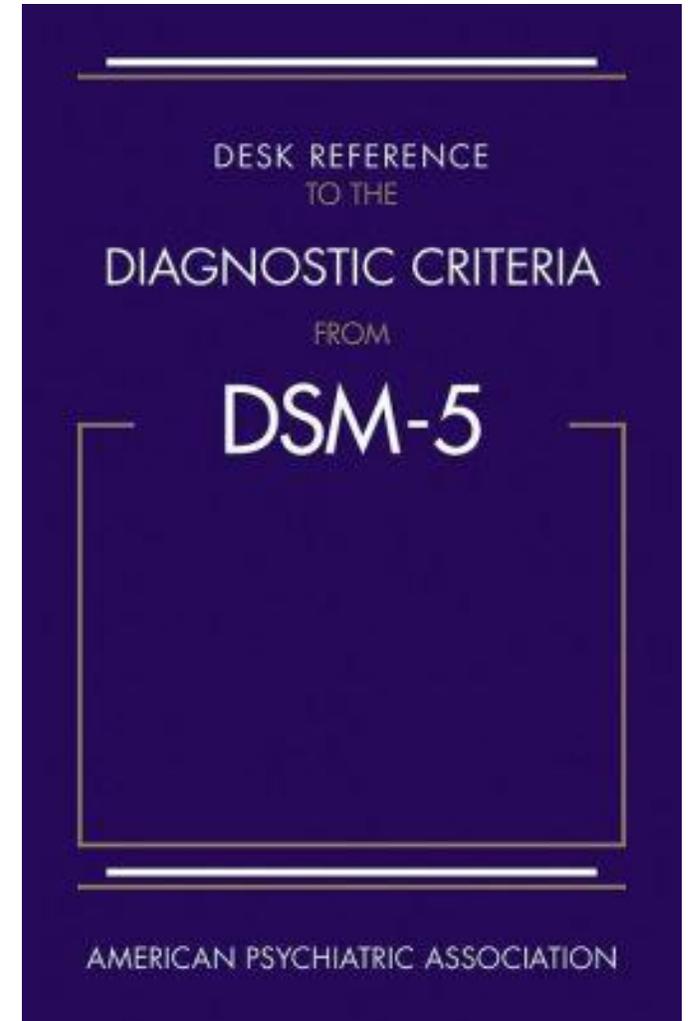
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# Tourette syndrome

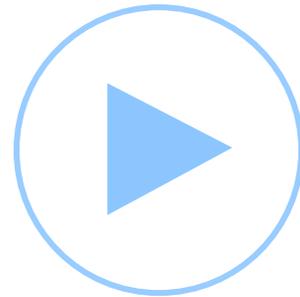
Tourette's Disorder 307.23 (F95.2)

- A. Both **multiple motor and one or more vocal tics** have been present at some time during the illness, although not necessarily concurrently.
- B. The tics may wax and wane in frequency but have persisted for **more than 1 year** since first tic onset.
- C. Onset is **before age 18 years**.
- D. The disturbance is **not** attributable to the physiological effects of a substance (e.g., cocaine) or another medical condition (e.g., Huntington's disease, postviral encephalitis).



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Where does it all begin ?



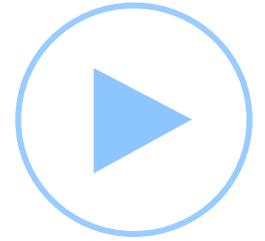
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TOURETTE  
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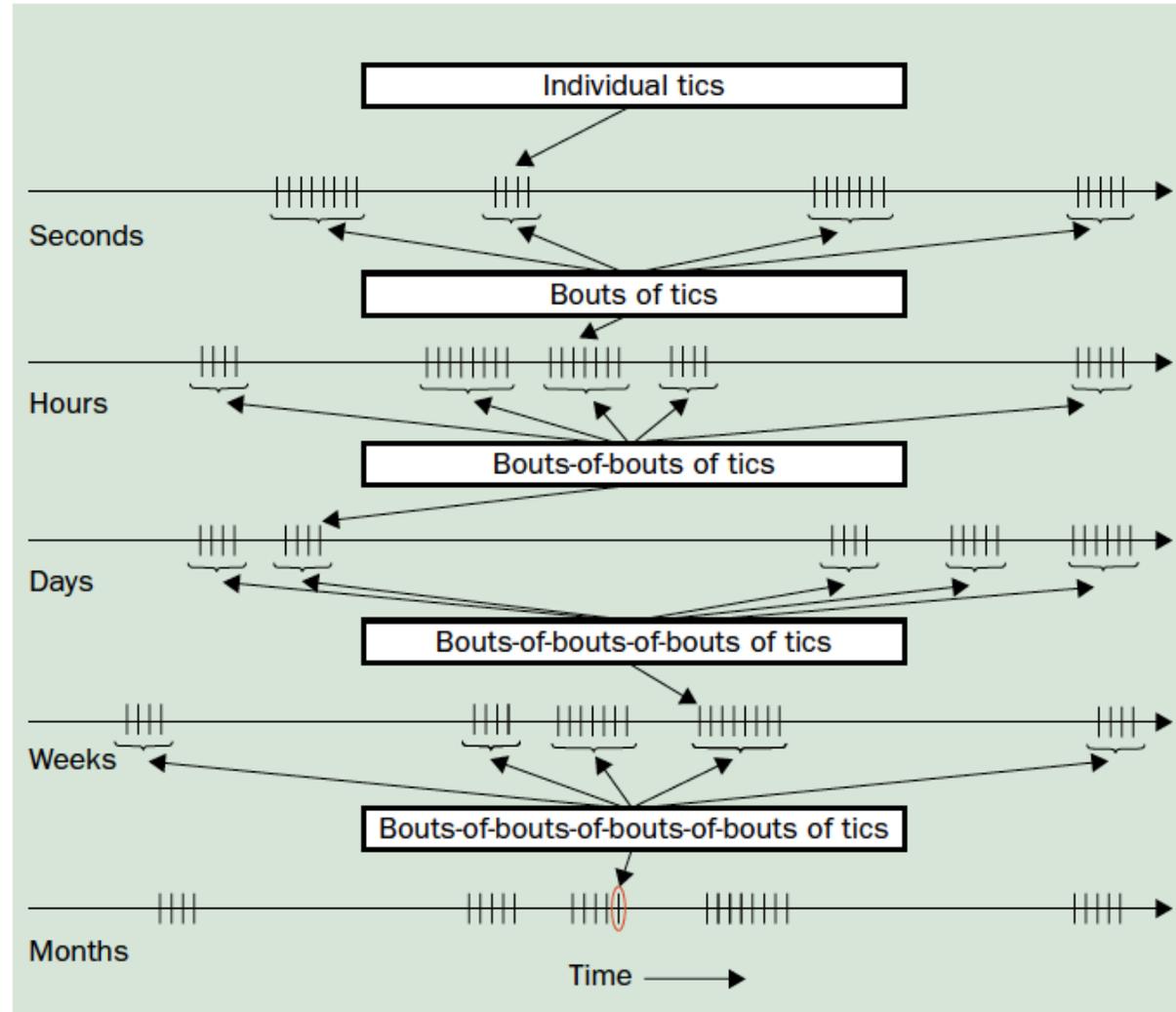


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Where does it all begin ?



# Temporal occurrence of tics



Seminar

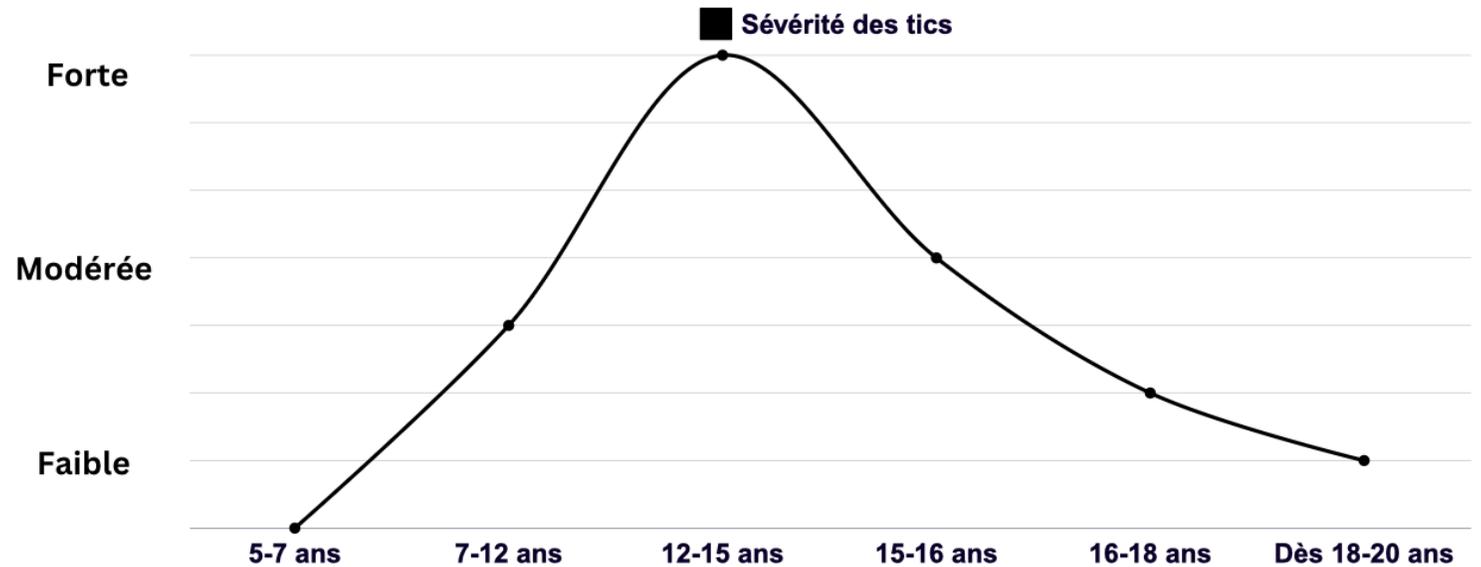
## Tourette's syndrome

James F Leckman

Lancet 2002; 360: 1577-86

Figure 1: **Fractal character of temporal occurrence of tics**  
 Progressively longer time scales (seconds to months) are depicted.

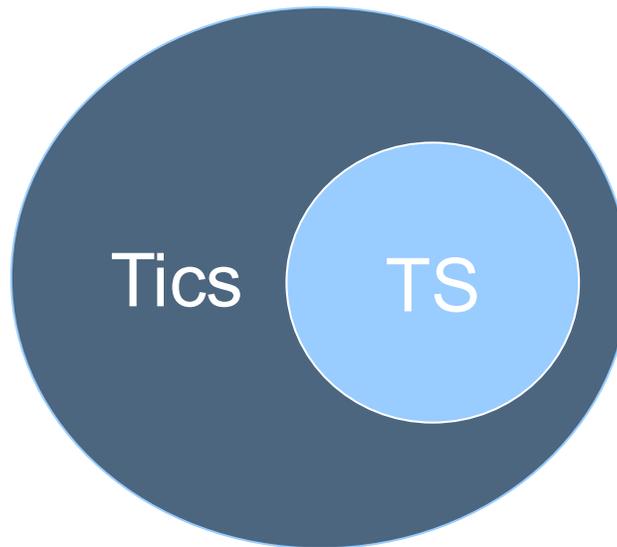
# Natural history of TS



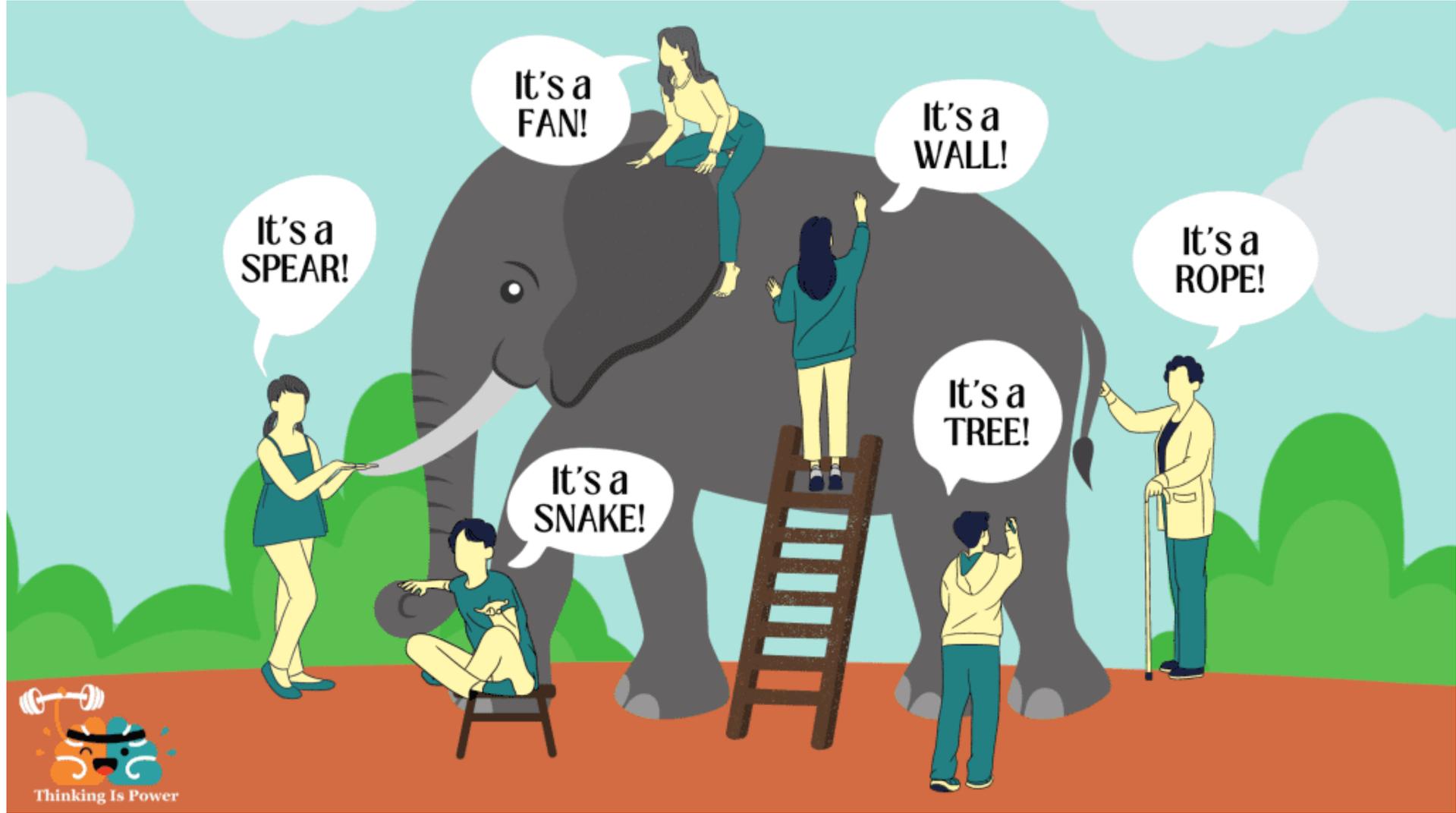
- Begins in childhood
- Severity peak during adolescence
- Significant reduction/arrest at adult age in 75% of cases

# Epidemiology

- 0.3-0.8% of school age children
- Transient motor tics during childhood: 15-25%
- M:F ratio - 4:1



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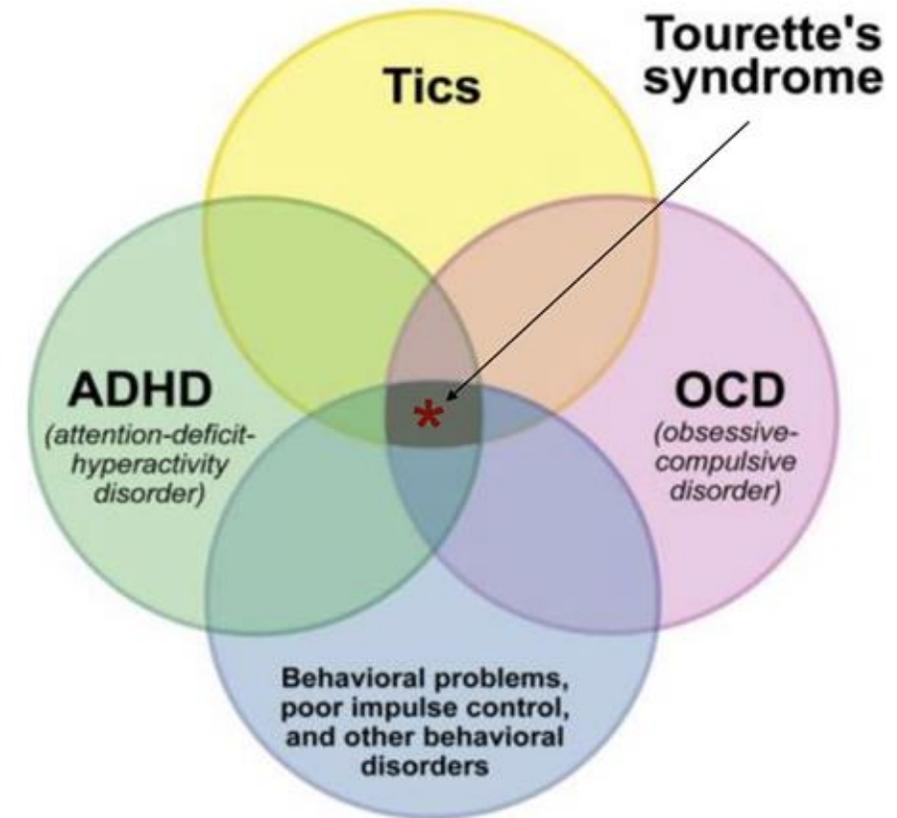


# Tourette syndrome (TS) - more than 'just' a movement disorder

*JAMA Psychiatry.* 2015 April 1; 72(4): 325–333. doi:10.1001/jamapsychiatry.2014.2650.

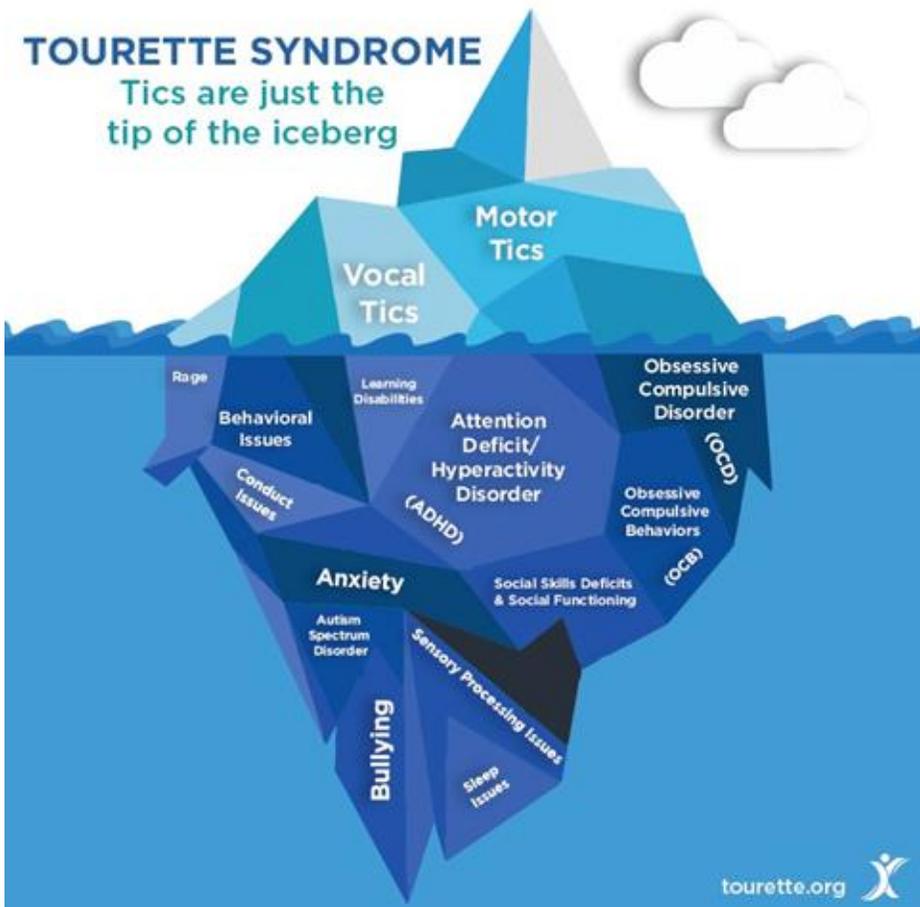
## Lifetime Prevalence, Age of Risk, and Etiology of Comorbid Psychiatric Disorders in Tourette Syndrome

Matthew E. Hirschtritt, M.D., M.P.H.<sup>1,\*</sup>, Paul C. Lee, M.D., M.P.H.<sup>2,\*</sup>, David L. Pauls, Ph.D.<sup>2</sup>, Yves Dion, M.D.<sup>3</sup>, Marco A. Grados, M.D.<sup>4</sup>, Cornelia Illmann, Ph.D.<sup>2</sup>, Robert A. King, M.D.<sup>5</sup>, Paul Sandor, M.D.<sup>6</sup>, William M. McMahon, M.D.<sup>7</sup>, Gholson J. Lyon, M.D., Ph.D.<sup>8</sup>, Danielle C. Cath, M.D., Ph.D.<sup>9,10</sup>, Roger Kurlan, M.D.<sup>11</sup>, Mary M. Robertson, M.B.Ch.B., M.D., D.Sc. (Med), F.R.C.P., F.R.C.P.C.H., F.R.C.Psych.<sup>12,13</sup>, Lisa Osiecki, B.A.<sup>2</sup>, Jeremiah M. Scharf, M.D., Ph.D.<sup>2,14,15,16,#</sup>, Carol A. Mathews, M.D.<sup>1,#</sup>, and for the Tourette Syndrome Association International Consortium for Genetics



Jankovic, Joseph, Tourette's syndrome. *N Engl J Med* 2001; 345: 1184-1192

## TS – a complex neuropsychiatric syndrome



86%



- Had  $\geq 1$  neurodevelopmental or mental health comorbidities

58%



- Had two (2) comorbidities

•Hirschtritt et al, 201

## Clinical comorbidities



- ADHD 30-60%
- OCD/OCB 30-40%
- Anxiety disorders 25%-30%
- Conduct & ODD 10-30%
- ASD 5-10% (broader phenotype 20%)
- Mood disorder 10-20%
- Specific learning difficulties 23%
- Dyspraxia 2-6%
- Injury
- Migraine/headaches
- Sleep disorders
- Stereotyped movements
- Teeth grinding/bruxism
- Trichotillomania, nail biting/skin picking
- Speech delay/stuttering

## Quality of life in Tourette syndrome

- Lower quality of life than the general healthy population.<sup>1</sup>
- Associated psychiatric comorbidities, particularly ADHD and OCD, are often more disabling than tics.<sup>2</sup>
- In adults with TS, tic severity contributed little to quality of life.<sup>3</sup>

Screening and management of TS comorbidities are therefore crucial goals in this population.<sup>4</sup>



**Treat behavioral co-morbidities first if these are the main source of disability!!!**

<sup>1</sup>Storch et al., 2007; Jalenques et al., 2012 ; <sup>2</sup>Eddy et al., 2011; <sup>3</sup>Muller-Vahl et al., 2010 ;

<sup>4</sup>Pringsheim et al., 2009; Ganos and Martino, 2015

At school/In the classroom



## Age-related observations

- Tics and Tourette Syndrome can cause difficulties for students from **elementary school through high school**.
- Increased academic demands > difficulties often become **more apparent in secondary education**. Younger students may be able to **mask their symptoms**.
- Older students often **make greater efforts to suppress or hide their tics** due to a greater need for **acceptance from peers**



## Tics and TS can affect students on multiple levels

- **Concentration:** Tics can distract students, compromising their concentration in class and **especially** during **tests**.
- **Relationships with peers:** Peers may **not understand** the nature of tics and may **tease, mock, bully and isolate** students.
- **Completing school assignments:** Frequent tics can affect students' ability to **keep up with the pace** of the class.
- **Stress/Anxiety:** Students often worry about when they might have tics and how others will react to them, resulting in **increased anxiety**.



## Also...

- Difficulties with transitions
- Difficulties completing homework
- Difficulty following instructions
- Discrepancy between verbal and practical performance
- Deficits in executive functions (organisation)
- Dysgraphia
- Explosive behaviour
- Impulsivity
- Oppositional behaviour
- Perfectionism/compulsive behaviours



What can **educators** do to support students with Tourette Syndrome or other tic disorders?



## Basic principles

- Communication and harmonious **collaboration** between the **family**, **school**, and the **therapists supporting** the child is of critical importance > **improvement** of their school performance & functioning
- Interventions should be **individualised** according to the needs of each student
- Teachers play a crucial role, as well as **other professionals** who interact with the student at school: **school principal**, **special education teachers**, **school nurse**, **psychologist**, **school social worker**, and even **support staff** (cafeteria staff, cleaning staff, etc.)



# Practical guidelines: the role of the educator

## 1. Knowledge

Recognise that these are **involuntary movements and sounds** of neurological origin, with periods of remission and exacerbation.

Tics can **change** forms **unpredictably**.

Although some students **manage to suppress** tics, this is **not feasible long term**. It requires **great effort**.

**Remember: Tics are involuntary and do not occur purposefully.**



## Practical guidelines: the role of the educator

### 2. **Ignore** as many tics as you can. This way:

- The student's **anxiety is reduced**, as they may be embarrassed or worried about possible consequences.
- The student's anxiety is reduced, which can lead to **a symptom reduction**.
- The likelihood of **bullying is reduced**.
- You demonstrate acceptance of symptoms in practice, thus **avoiding stigma**.
- You function as a **role model** for the **classroom's behaviour**



## Practical guidelines: the role of the educator

- 3. Try to reduce anxiety and stress.** Anxiety exacerbates symptoms. If you identify factors that increase anxiety and take supportive measures, symptoms often decrease.
- 4. Identify skill deficits that may contribute to anxiety and intensification of tics** (specific learning difficulties, deficits in organisational skills), as well as strategies for addressing them.
- 5. Support in writing if needed (dysgraphia):** e.g., using a computer, help from a support teacher, avoiding laborious copying, **oral examination**).
- 6. Pay attention to co-occurring difficulties (e.g., ADHD, OCD, ASD).** The symptoms of these disorders may require treatment and may create **greater problems** than the tics themselves.



## Practical guidelines: the role of the educator

7. **Be creative with interventions**, depending on the difficulties of each student (e.g., with OCD symptoms).
8. **Involve the student**: if tics are particularly intense or bothersome (e.g., spitting, swearing, inappropriate touching of others), try to think of possible solutions together with the child. Parents or specialist therapists working with the child may help here.
9. **Allow the student short breaks outside the classroom if this helps them.**
10. **Seat selection in the classroom**: some students will prefer to sit in a place where their tics are **not easily visible**, or with easy exit access if they need to **take breaks**.



## Practical guidelines: the role of the educator

- 11. Tests/Examination:** offer the opportunity to take exams in a **separate area**, so they can tic without the stress of being exposed or bothering their classmates.
- 12. In cases of anxiety during transitions:** facilitate the student by providing more time or preparation.
- 13. Sensory particularities**
- 14. Contribute to educating the rest of the school staff and classmates about tics:** with the student's consent, educate the class about the nature of tics with the aim of classmates' understanding and **avoiding bullying**.



## What **not** to do

- **Do not make comments and do not punish the student for their tics.** Remember that these are **involuntary** movements or sounds of neurological origin. Children **do not tic purposefully, nor** are tics **under their control**.
- **Do not set as a goal the reduction of the student's tics in class.** Although tics may sometimes be **disruptive** to the student themselves or their classmates, **avoid setting goals** to reduce tics at school.



## A quick recap?

- If possible, **ignore** tics
- **Never** admonish, or even **punish** the child
- Be **supportive** and **encouraging**, underlining the child's strength, **instead of being the "tic police"**.
- If necessary, **allow** the student to **leave class** to evacuate tics
- However: tics and impulsivity (ADHD) **are not a go free card for inappropriate behavior**
- Be **just**, but **firm**. And expect the **same** from children with tics as from non-ticcing children



## Thank you for your attention!

For more information:

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European Society for the Study of Tourette Syndrome

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