

17<sup>th</sup> International Conference on Tourette Syndrome & Tic Disorders

ESSTS

TS-school  
*Athens*



TS-school Athens | Tuesday, 20<sup>th</sup> May 2025, Eugenides Foundation

How to answer FAQ from patients and families on etiology and pathophysiology of tic disorders

Disclosing a Diagnosis of Tourette Syndrome-the challenges

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What are the key components of giving diagnosis?



## Get it right....

- Full history history history....
- Review Case and ensure consistent
- If in Doubt 'call a friend'!
- Consider the wider differentials
- Co-occurring conditions
- Is it Functional?



## Prepare the environment

- Quiet space
- Room to listen
- Ensure all key people are present/ or are supported at the point of delivery
- Assess any stigma/ pre-conceived ideas/ concerns about labelling
- Assess what labels the child/family prefer
- Provide written leaflets from the support organisations to take away



# Neuro-Affirmative?

- Examples



# Communication

- How complex?
- Adjust for age of patient
- Story of Mr Tourette?
- How much detail?-no right or wrong and need to be flexible
- Empathy and understanding



## How do we explain?

- Volunteer?



## Diagnosis-

- Neurological
- Neurogenetic underpinnings-linked to OCD/GAD/Stammer and not just tics
- Tics – repetitive, involuntary movements and sounds
- Not a Spectrum of severity!!
- Common misconceptions



## Discuss warning signs for co-occurring conditions

- Beware not to scare!
- Often needs to be tailored to the history



## Neuro-Affirmative

- Non 'Brain damaging'
- Normal lives for many
- Good careers and happiness levels in many
- What determines success ?
- Acknowledge the resilience and challenges many face



## Discuss the Management Options

- Support services
- Treatments available when needed
- Provide contacts
- Challenges with access to services so discuss in regions



## Case Sharing- examples

- Fabrication
- Functional TS and FTLB
- PANS
- Blue badges / Disability/ Work/ School letters



## Common Questions asked ?

- Why me?
- How do I tell people without being embarrassed?
- How do I control my tics?
- How do I stop stigma? Anger?
- What causes TS?
- How do I stop bullies?
- What is the difference between TS and FTLB?



# Summary

- Clarity and Documentation
- Teamwork
- Empathy
- Reflection
- Lifelong learning

