



Healthcare
Conference
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The impact of Tourette Syndrome on lives and the need for better healthcare pathways



Dr Ed Palmer

Psychiatrist and researcher, University of Birmingham; and Vice chair, Tourettes Action Board of Trustees



Ione Georgakis

Therapies and advocacy manager, Tourettes Action

#bettercarecostsless

Introduction to Tourette syndrome

GS1UK Conference



Overview

- What is Tourette syndrome
- Co-occurring conditions
- Current Challenges
- Myth Busting
- Support available from Tourettes Action
- Q&A



What is Tourette syndrome?



What is Tourette syndrome?

- Tourette syndrome is an inherited neurodevelopmental condition
- The key features are tics
- A tic is a production of an involuntary sound or movement
- For a diagnosis, multiple motor (movement) and at least one vocal (sound) tic must be present for over 12 months



Tic categories

| | Motor Tics | Vocal (phonic) Tics |
|---|---|--|
| Simple Single stage sounds or movements | <ul style="list-style-type: none"> • Eye blinking • Eye rolling • Grimacing • Shoulder shrugging • Limb jerking • Abdominal tensing • Head jerking | <ul style="list-style-type: none"> • Whistling • Throat clearing • Sniffing • Coughing • Tongue clicking • Grunting • Animal sounds |
| Complex Multistage sounds, words or vocalisations | <ul style="list-style-type: none"> • Jumping • Twirling • Touching objects and other people • Throwing • Clapping | <ul style="list-style-type: none"> • Words • Phrases • Sounds • Speaking in accents • Sentences • Singing |

| Other Tics |
|---|
| Ecophenomena |
| Palaphenomena |
| Coprophenomena |
| Non-obscene socially inappropriate behaviour (NOSI) |



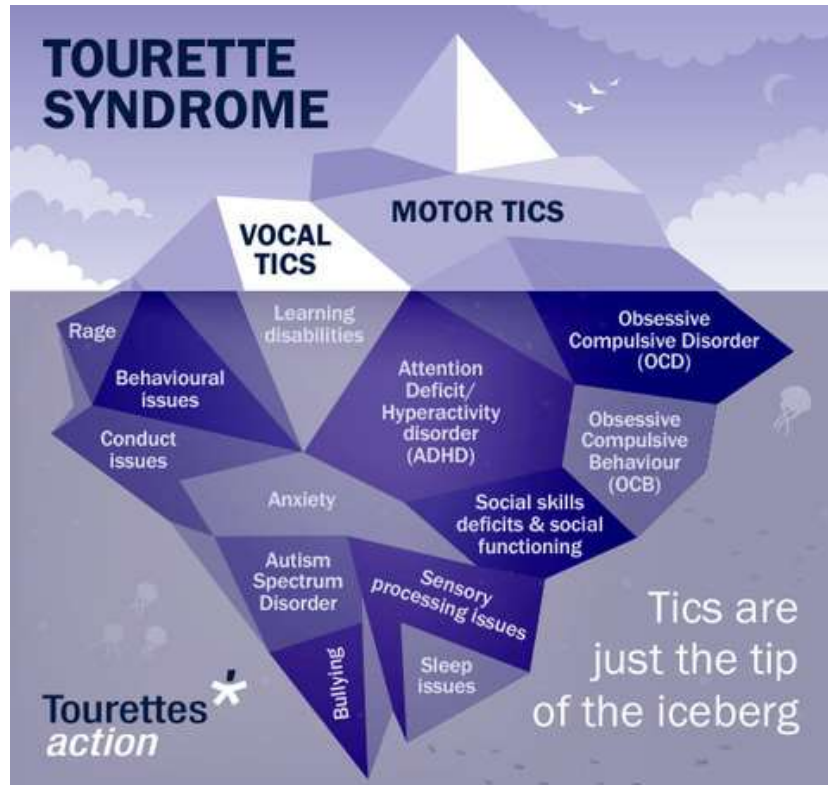
Contributing Factors



The spectrum of severity



Co-occurring conditions



85% - 90% of people with TS have another co-occurring condition or secondary disability

- Attention Deficit Hyperactivity Disorder (ADHD) 54%
- Obsessive-compulsive disorder (OCD) 50%
- Anxiety 30-36%
- Autistic spectrum disorder 11% - 50%
- Sensory processing differences 80%
- Insomnia 64%
- Rage 25-70%
- Pain 99-100%

For many, the co-occurring conditions can be more challenging than the tics



***"When you've met one
person with Tourette's
you've met one person
with Tourette's"***



Current Challenges



Diagnosis and referral Pathways: The Ideal

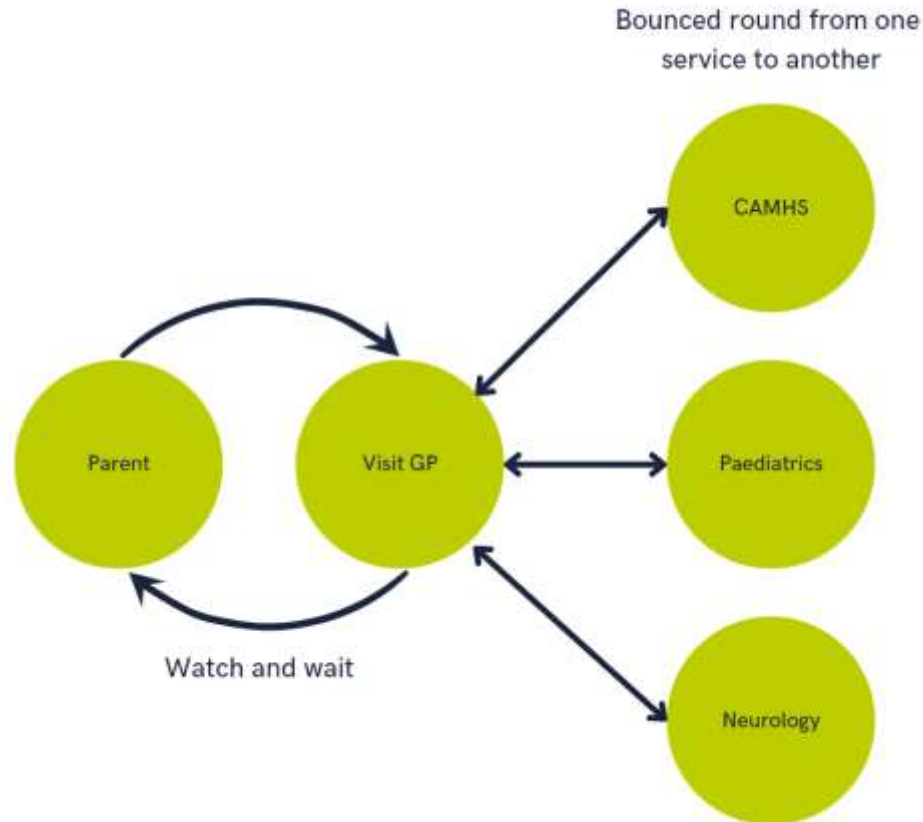


- Who can offer;
- Assessment and diagnosis
 - Referral and access to psychological intervention i.e. CBIT
 - Initiation, titration and monitoring of medication
 - Long term follow-up

Only a few of these services in the UK exists, all in the South East, post code lottery



Diagnosis and referral Pathways: The Reality



1
Seek out of area referral

2
Pay for private care

3
Do nothing



- **No NICE guidelines to assist primary care**
- **Post code lottery**
 - All specialist services are in the South East (hopefully one coming to Liverpool)
 - 12/17 specialist doctors are in the South East
- **Huge waiting times - Our survey results 1034 responses National findings:**
 - 56% of people who received a diagnosis waited longer than 1 year
 - 29% of people who received a diagnosis waited more than 2 years
 - 19% of people who received a diagnosis waited more than 3 years!
- **No follow up**
 - 52% said that they were **diagnosed and then discharged at the same appointment** and provided with **NO ongoing care**



Myth Busting



Myth Busting

The myths which surround Tourette syndrome can cause the following challenges

- Underdiagnosis
- Stigma
- Shame
- Misrepresentation

We want to end the stigma and help people with Tourette's be accepted for who they are.



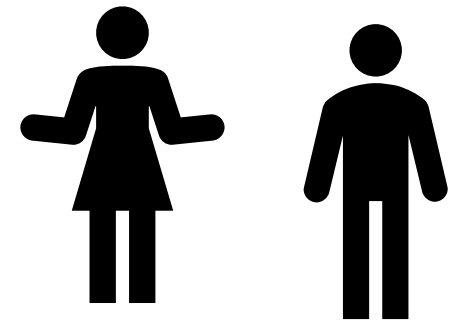
Myth Busting

Myth

Tourette's only affects males

Fact

Although Tourette's is more common in males 4:1, it affects both sexes



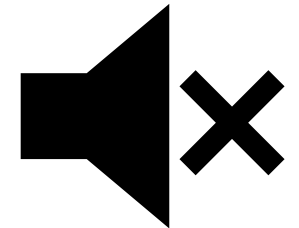
Myth Busting

Myth

Everyone with Tourette's swears

Fact

Around 15-20% of people with Tourette's have coprolalia



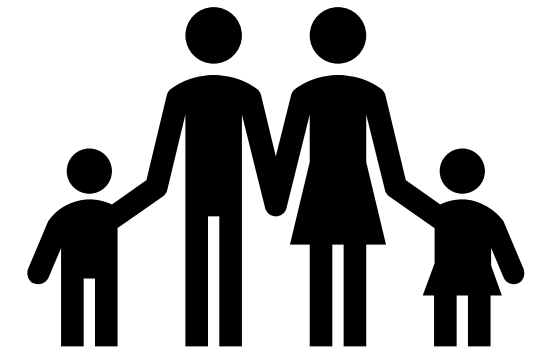
Myth Busting

Myth

You will grow out of it

Fact

Tourette's is a lifelong condition, however 50% of adults tell us that their symptoms do improve into adulthood



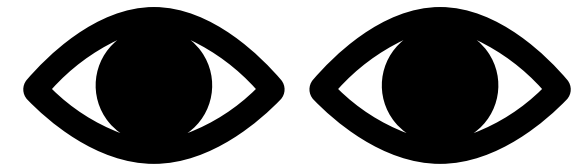
Myth Busting

Myth

We should only focus on the tics we see

Fact

Internal and invisible tics can be painful and distracting. We must support and accommodate **all** tics



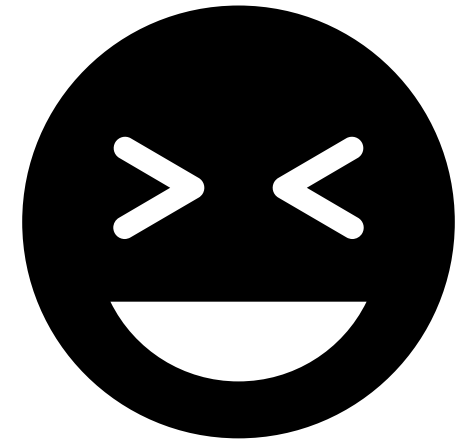
Myth Busting

Myth

Tourette's is funny

Fact

Tourette syndrome can cause physical and mental barriers to wellbeing. It is not a punchline



Myth Busting

Myth

Tourette's is rare

Fact

Tourette syndrome impacts around 1% of the international population, 300,000 people in the UK and around 1:100 school aged children.



Myth Busting

Myth

Tourette's is a behavioural condition

Fact

Tourette's is a neurodevelopmental/neurological condition. It is **not** 'naughtiness'



Myth Busting

Myth

Tics are what the person is thinking

Fact

Tics can be influenced by many internal and external factors, they are involuntary and NOT what the person is thinking or believes



How can Tourettes Action help?



How can Tourettes Action help?

[School, business, and employer training](#)

[Peer training and Social Story's](#)

[TA Tic and Tic Attack Passports](#)

[TA events](#) – Tics fest, teen fest and adult weekends

Free [online training](#)

[TA grants for specialist equipment](#)

[TA ID card](#)

[Online and face to face support groups](#) – children, adults and families

Guidance on [employment](#) for people living with Tourette's and Information for [employers](#)

[Lived experience stories](#) and content via our website and social media

Sign up for our [E-Newsletter](#) to keep in the loop with the latest support and research updates



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www.tourettes-action.org.uk



help@tourettes-action.org.uk



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