

Understanding Tourette Syndrome (TS)

Health and Social Care professionals



Introduction

HELLO
my name is

Ione Georgakis (She/Her)
Tourettes Action Advocacy Lead
Occupational Therapist

I have Tourette Syndrome



Introduction

HELLO
my name is

Lucy Toghill (She/Her)
Tourettes Action Education
Manager

I have a child with Tourette Syndrome

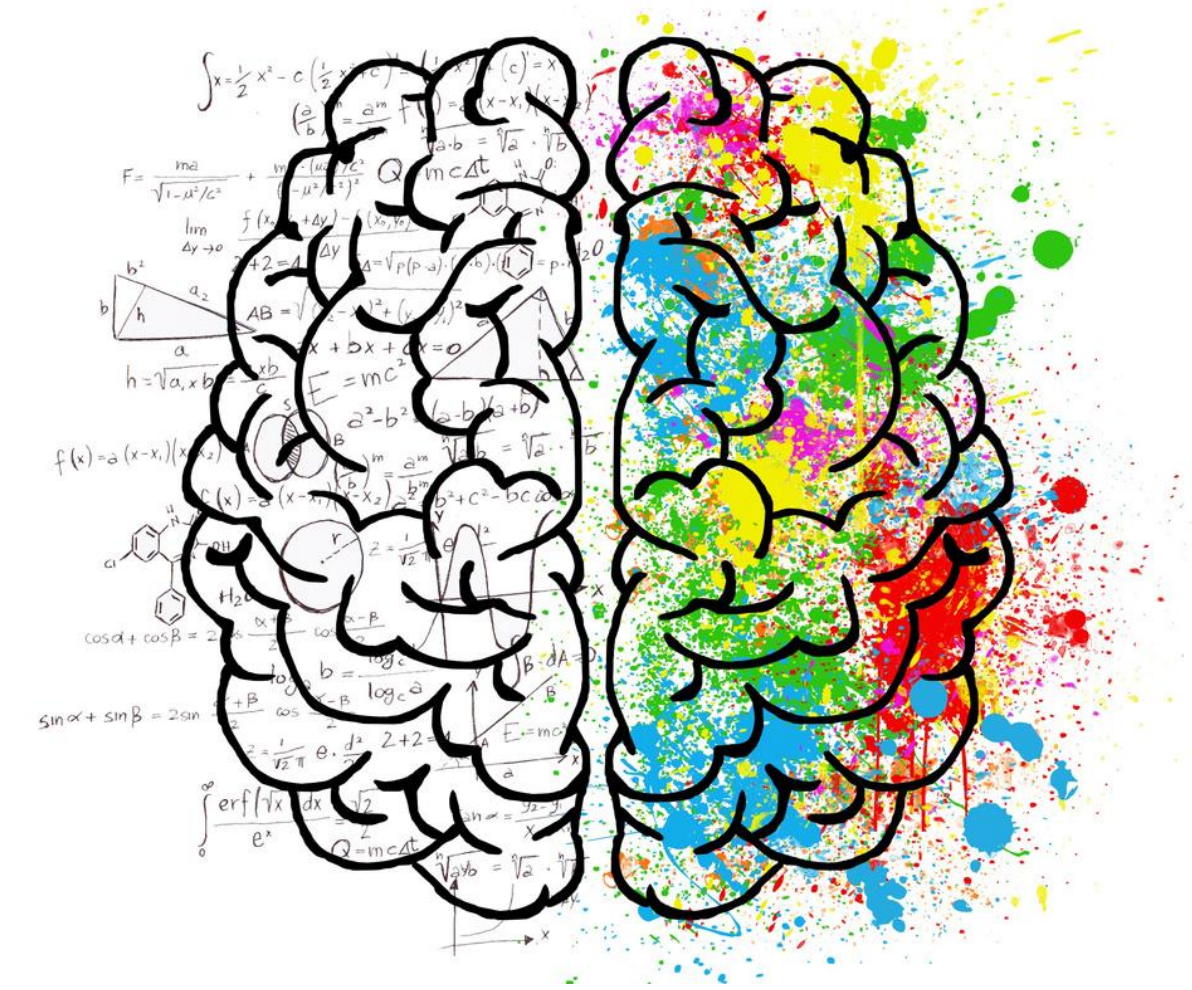


- What is Tourette Syndrome
- Diagnosis
- Co-occurring conditions
- Contributing factors
- Tourettes impact on the individual and the family
- Support available
- Pick our brains Q&A



What is Tourette Syndrome?

- Tourette Syndrome (TS) is a genetically determined neurological condition.
- The key features are tics.
- A tic is a production of an involuntary **sound** or **movement**
- Tics typically start around the age of 6/7 years and tend to peak around early adolescence



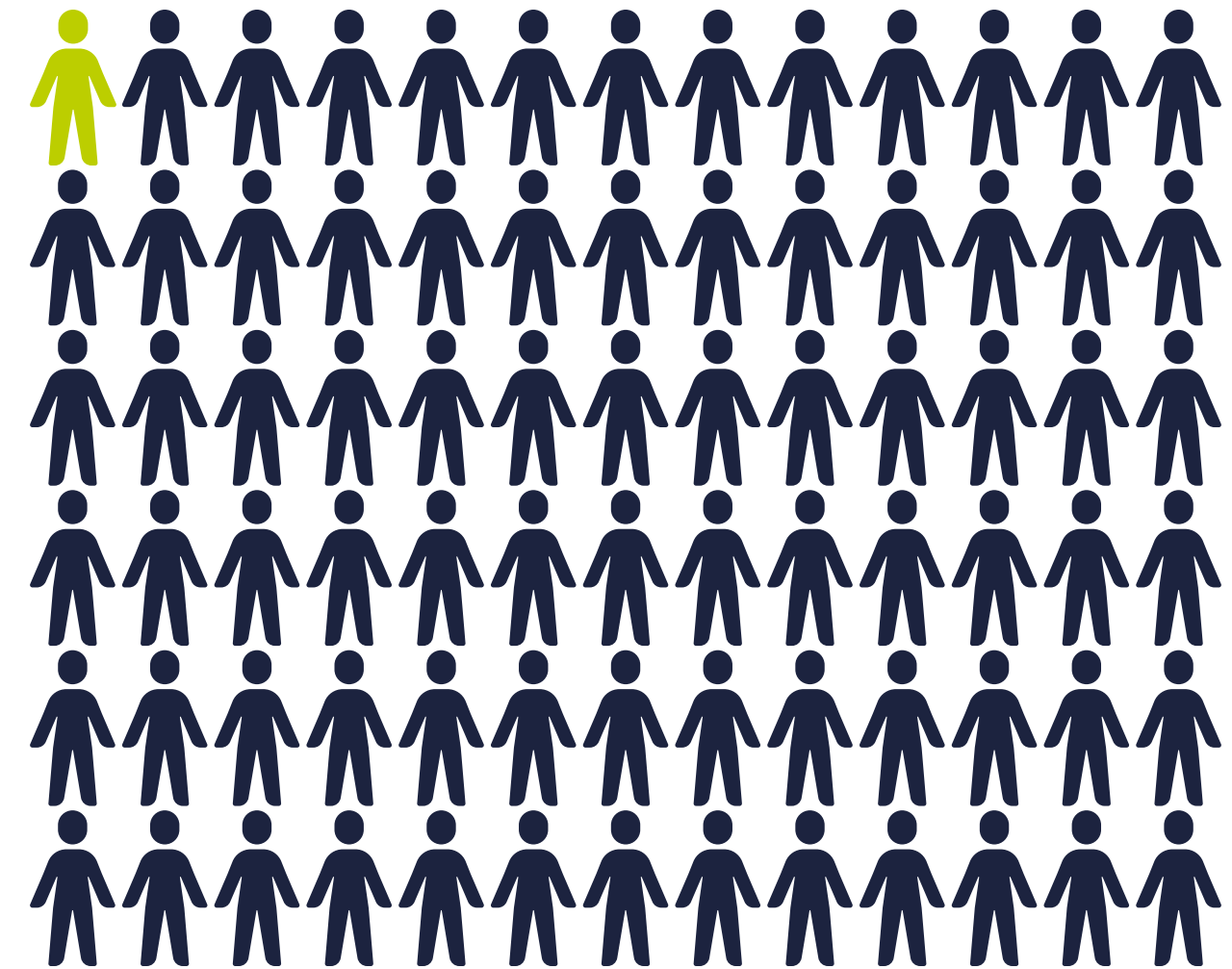
Prevalence of TS

TS affects roughly 1% of the population and 1 in 100 school children.

Recent US research indicates estimates to be as high as 1 child in 50

There are over 300,000 people in the UK living with TS.

Similar prevalence to Autism and childhood epilepsy.



	Motor Tics	Vocal Tics
Simple	Eye blinking Eye rolling Grimacing Shoulder shrugging Limb and head jerking/head nodding Abdominal tensing	Whistling Throat clearing Sniffing Coughing Tongue clicking Grunting Animal sounds
Complex	Jumping Twirling Touching objects and other people Copropraxia Echopraxia	Words or phrases Non obscene socially inappropriate (NOSI) behavior Coprolalia Echolalia

Vocal (or Phonic)

Sounds

Motor

Movements

Simple

Single-stage movements or words

Complex

Multistage movements or words

Echo-phenomena Repeating sounds and movements

Copro-phenomena Obscene words or gestures



What is Coprophenomena

Coprolalia: an involuntary, uncontrollable outburst of obscene or socially inappropriate derogatory remarks. These can be verbal utterance of obscenities (Swear words), sexual words and connotations or religious and racial slurs. This also includes 'mental coprolalia' which describes repeated thinking of obscenities and profanities.

Coprographia: the compulsion to write down obscenities and profanities

Copropraxia: the uncontrollable performance of obscene gestures

Although these symptoms only impact 15-20% of people with Tourettes it is possibly the most tricky type of tic to manage.



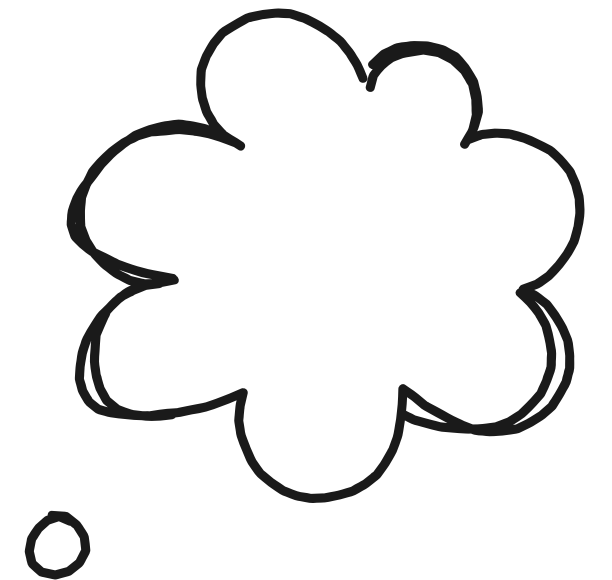
Other tics

- **Palilalia** – repetition of the person's own words or phrases
- **Palipraxia** - repetition of the person's own movements
- **Echolalia** – involuntary repetition/imitation of another person's spoken words
- **Echopraxia** – involuntary repetition/imitation of another person's movements



Hidden Tics

- **Visual tics** e.g. looking at shadows/counting objects.
- **Intrusive thoughts** e.g. harming someone or themselves.
- **Suggestive tics** e.g. overwhelming urge to follow through with inappropriate suggestions.
- **Thought tics** e.g. something we all think but young people with TS can't regulate. (It can be a bit like having a window into their soul).
- **Conversational/contextual** e.g. these can sound and appear to be in the correct context but they just find it very hard to switch off their regulator button. Sometimes these tics can be completely random and not something a young person is thinking about at all.
- **Internal tics** e.g. clenching stomach muscles or jaw



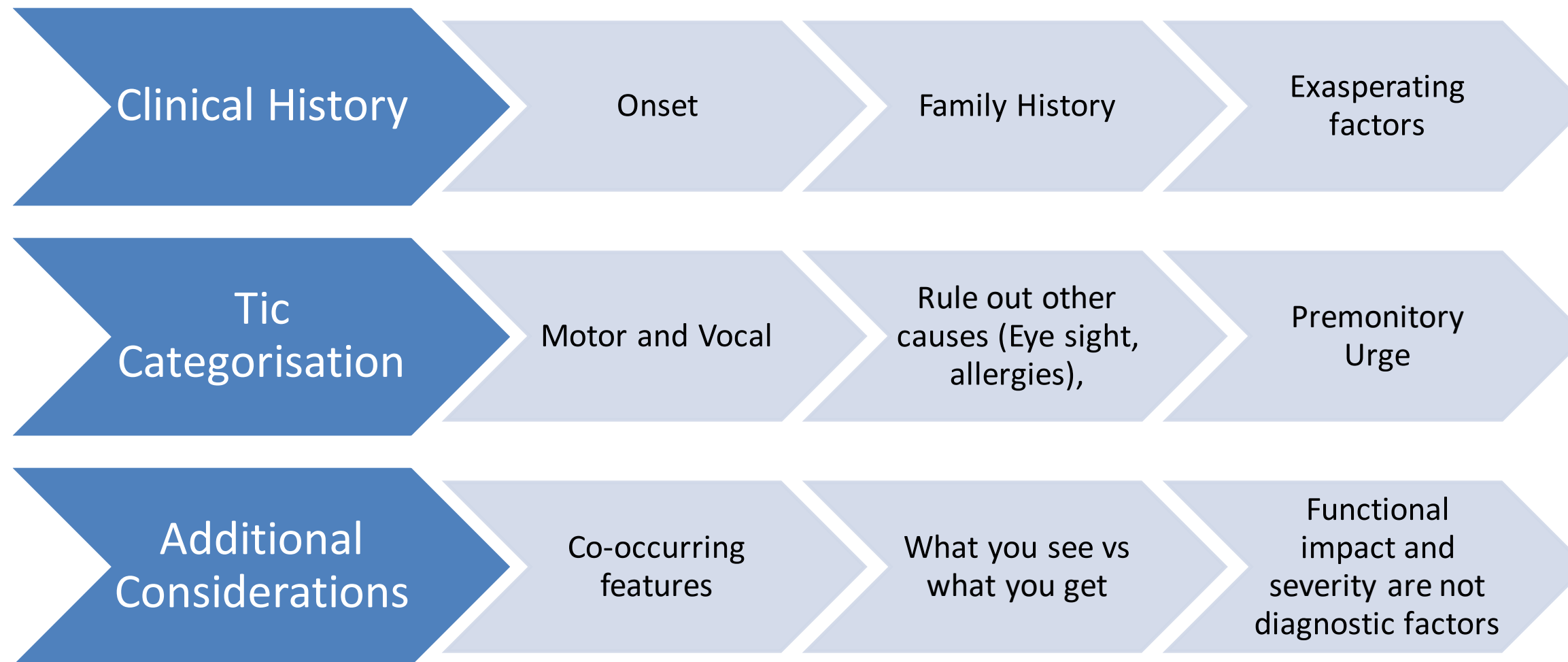
Other tic disorders

Having Tics doesn't always mean Tourette Syndrome. Tourette Syndrome is on the spectrum of conditions known as Tic Disorders.

- Transient tic disorder (**Provisional**) – vocal OR motor tics that tend to be transitory. Tics only last a few weeks or months.
- Persistent tic disorder (**Chronic**) – vocal OR motor tics that tend to persist rather than be transitory. Tics occur for more than 1 year
- A tic disorder (**not specified**) - tics are present but do not meet the criteria for any specific tic disorder
- Sudden Onset or Functional Tic/Neurological Disorder



Making a diagnosis



Key Diagnostic Factors

- Early age of onset (3-8 years)
- Male gender 3:1
- Family history of OCD, TS, ADHD
- Motor tics (eye blinking, facial grimacing, shoulder shrugging)
- Vocal Tics (sniffing, coughing, throat clearing)
- Waxing and waning tics
- Co-occurring diagnosis (Only 12% have pure TS)



What does a tic feel like?



An itch you
can't scratch



Eating a sugar
donut



Not
blinking



Holding back a
sneeze



Can tics be controlled?

Although tics are completely involuntary, some people are able to suppress their tics for a short time. However, this can be very difficult.

What is suppression?

A helpful way of understanding this is to compare it to a blink, cough, yawn, sneeze or scratch. For a short period of time, it is possible to keep your eyes wide open and avoid blinking but eventually, you will have to blink as the urge is too strong to control.



Activity

It can be extremely painful and uncomfortable to suppress a tic



Try not to blink and keep your eyes open
for a whole minute.

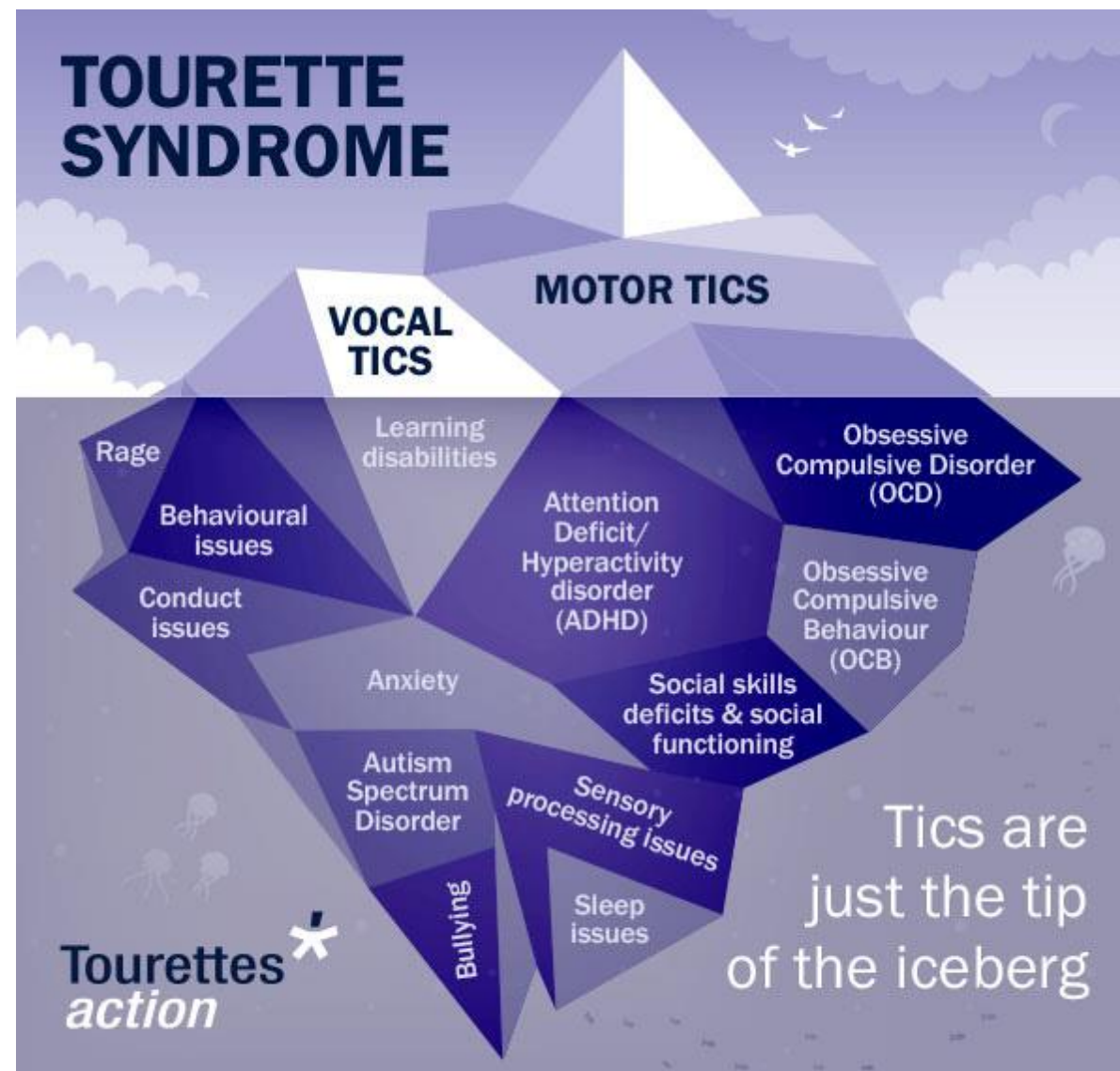
How easy was it?

How did it make you feel?

Now imagine you are at work,
school, or at an important
meeting. How might this impact
you?



Co-occurring features



85% of people with TS have another co-occurring condition

- Attention Deficit Hyperactivity Disorder (ADHD) **54%**
- Obsessive-compulsive disorder (OCD) **50%**
- Anxiety **30-36%**
- Autistic spectrum disorder **2.6% - 11%**
- 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



Negative Cycle

Where do you think
the best place would
be to break this cycle
and intervene?



Tics vs Neuro-typical 'Bad' Behaviour – The magical question!

- Tics can sometimes appear to be in context. You may need to ask the child.
- Bad behavior alongside TS can be a sign of the child trying to regain some control and distracting from their tics.
- Remember, all behavior serves a purpose. What need might your child be trying to get met (Being removed from the classroom? Distracting from the tics?)
- Talk after/ask child ...What happened? Why do you think that happened? How can we help you next time?
- If you're unsure, then assume it's a tic.
- Never punish a child for a tic.



What makes us tic?



THE SPECTRUM OF SEVERITY



Influences on tics

Tics generally wax and wane, however, some internal and external factors can impact tics

Increase

- Stress
- Anxiety
- Being around others who tic
- Talking about tics
- Tiredness
- Excitement
- Alcohol
- Hunger
- Pain
- Changes in the sensory environment

Reduce

- Mindfulness and Meditation
- Being engrossed in a task/distracted
- Feeling relaxed and accepted
- Avoiding triggers
- Exercise
- Environmental adjustments



The additional impact of Tourettes



Fatigue

Suppression and
tics



Embarrassment

It doesn't matter
that it is
involuntary



Prejudice

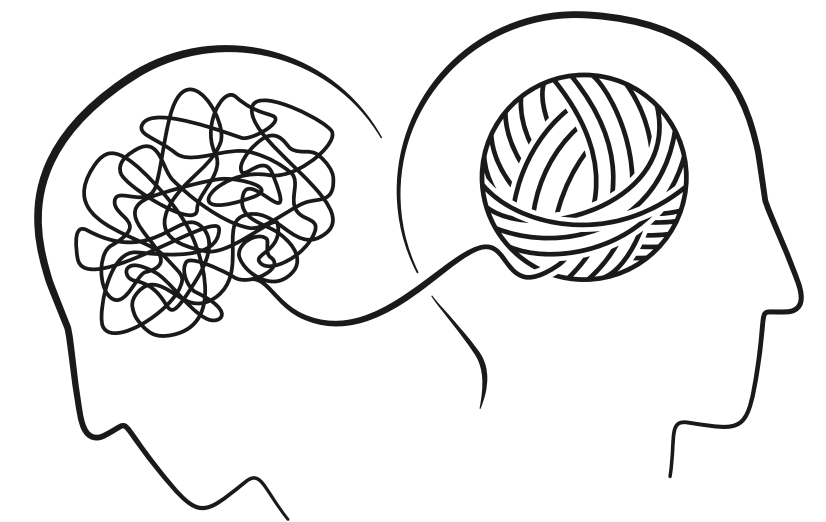
Removed from
venues/Threatened



Mental Health

Tourette Syndrome is not a mental health condition, but it can certainly affect a persons mental health.

- Mental health conditions are much more prevalent in the TS community than the general population.
- The huge amount of stigma surrounds TS, often limits the confidence and self-esteem of those diagnosed.
- People with TS are over 4 times more likely to die by suicide.
- Patients with TS report higher rates of substance misuse, and self injurious behaviours.

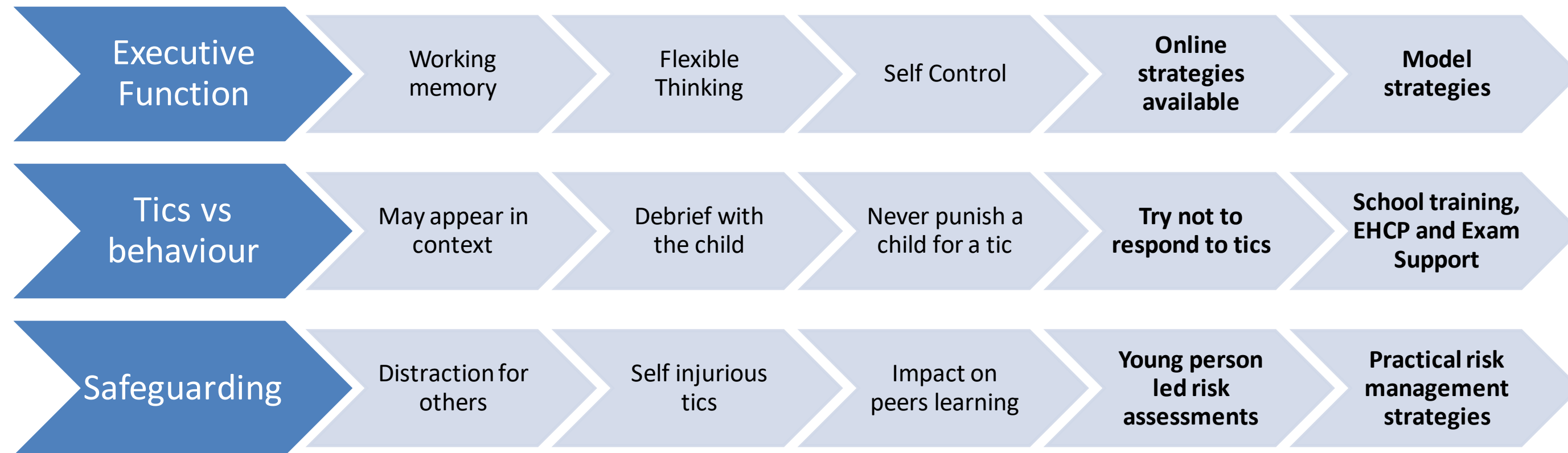


Support



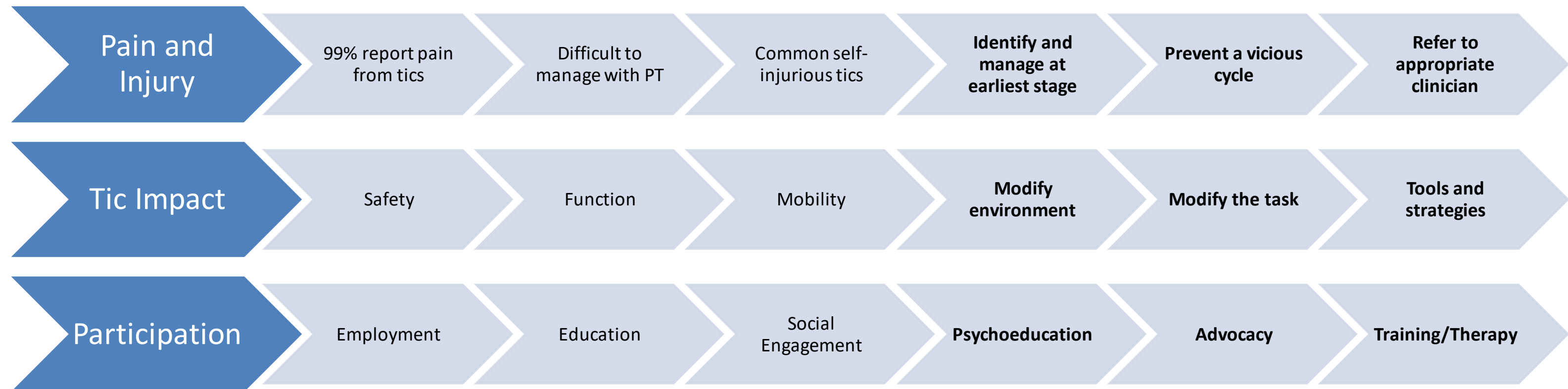
Educational challenges and strategies

TS does not in itself affect IQ, but it can influence a person's ability to learn, and safely engage with the world around them.



Functional challenges and strategies

Many people with TS report difficulties in safely and effectively accessing the things they want and need to do.



***"When you've met
one person with
Tourettes you've met
one person with
Tourettes"***



Therapies Available

Comprehensive Behaviour Intervention for Tics, or CBIT, is a specialised behaviour therapy designed to help individuals learn to better manage their tics. Behavioural therapy is not a cure for tics. However, it can help reduce the number of tics, the severity of tics, the impact of tics, or a combination of all of these.

- **Psychoeducation** examining what situations tend to make tics worse and what situations make tics better. The goal is to use that knowledge to avoid the situations that exacerbate tics or to find ways to lessen their impact; then to encourage situations that lessen tic activity.
- **Self-awareness training** teaches the person how to self-monitor for early signs that a tic is about to occur using recognition of the premonitory urge.
- **Relaxation training** includes strategies that can be used to lessen stress and to assist in the management of phonic tics. This would include diaphragmatic (deep) breathing, progressive muscle relaxation and imagery.
- **Establishing a tic hierarchy** the therapist will help the person identify their most bothersome tic (not the tic that seems to bother someone else (the parent or teacher or spouse), but the tic that causes the person with symptoms the most discomfort, distress or difficulty.
- **Selecting a target tic and reverse engineering it** works with the person to recognize the premonitory urge that precedes that particular tic, and then they break down the tic into its components...what are the precise muscle movements involved in the tic from start to finish.
- **Formulating a competing response to the target tic using habit reversal techniques** CR is developed so the person can apply the CR performed without any external aids or devices when the urge for that tic is experienced designed to make performing the tic impossible
- **Social support** The support of the child's family, friends along with the child's educators is critical in achieving success.



Medication for Tourette Syndrome

Selecting treatment for TS is an individual process due to the wide range and severity of symptoms and the occurrence of associated conditions such as attention deficit hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD) and depression. Clinicians need to work closely with patients and their families when deciding on the most appropriate medication, in order to balance potential risks and benefits of treatment with medication.

The decisions that need to be made include:

- whether or not to treat;
- which symptoms to treat - tics or the other conditions such as ADHD or OCD
- whether a combination of medications is necessary to treat the different symptoms.

Assessing the effectiveness of treatment is complicated by the fact that tics naturally 'wax and wane', meaning that periodically they get better and worse over time. Sometimes therapies appear to be working well but this may be a period in which tics are naturally less severe.







Other approaches

- **Mindfulness and relaxation**
- **Botox**
- **Diet and exercise**
- **Manage Pain – Physio**
- **Manage Function – Occupational Therapy**



A guide to supporting a friend, family member, colleague or client with TS

-  **Be patient with me** – Sometimes, things might take a little longer. I might need extra time to process. Being rushed doesn't help.
-  **Talk to me** – We all have different ways of managing our conditions. Some people may not feel comfortable talking about their TS, yet others may find it helpful to discuss and process their experiences. Just ask.
-  **Do your research** – Having people around you who understand your condition can help you to feel supported and validated.
-  **Be an advocate** – When you hear misconceptions about TS, do your best to help dispel those myths. It's still so misrepresented; all we want is acceptance.



How can Tourettes Action help?

- School, organisational and employer training
- Peer training
- Social Story's
- TA Tic and Tic Attack Passports
- TA events – Tics fest, teen fest and adult weekends
- TA grants for specialist equipment
- TA ID card to help highlight your child's condition and needs
- TA guide to seeing a specialist
- Online and face to face support groups – children, adults and families
- Many resources for educators, families and young people with Tourettes
- Lived experience stories and content via our website and social media - You are not alone
- Sign up for our E-Newsletter to keep in the loop with the latest support and research updates





You can now take our free *Understanding Tourette Syndrome* course via our website. This can be a useful resource for personal CPD or for helping families, teachers or carers to understand the condition.

<https://www.tourettes-action.org.uk/155-elearning.html>



Take home messages

- Education and understanding are key
- Tics are not intentional attempts at gaining attention or being disruptive
- Tics are not the young person's or parents' fault
- Tics should not be taken personally they are Involuntary, and it is not what the person is thinking
- Co-occurring conditions can have a significant impact
- Young people should not be punished for their tics.
- Tics are not simple habits that can easily be replaced or stopped.
- There is no one-size-fits-all “cure” for tics.



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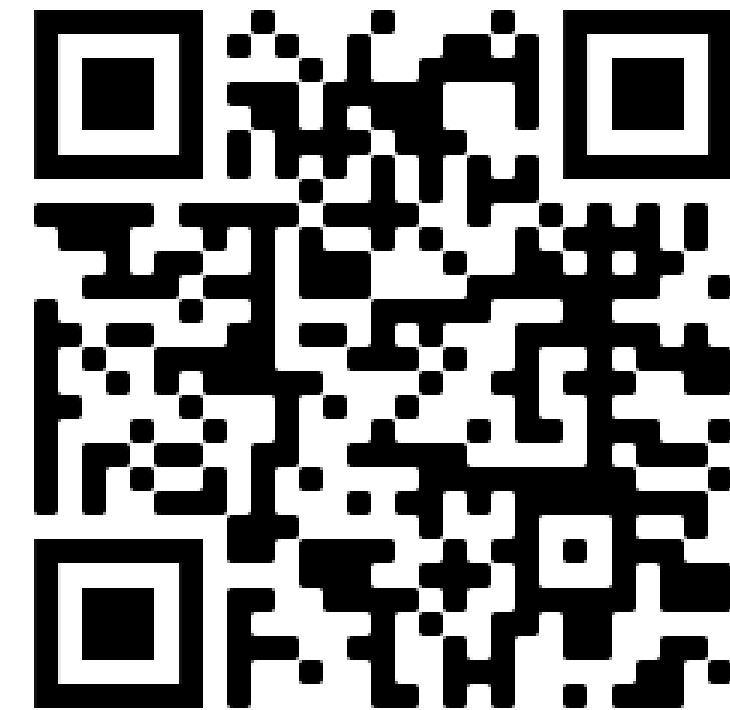
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