

Things people say to someone with Tourette Syndrome

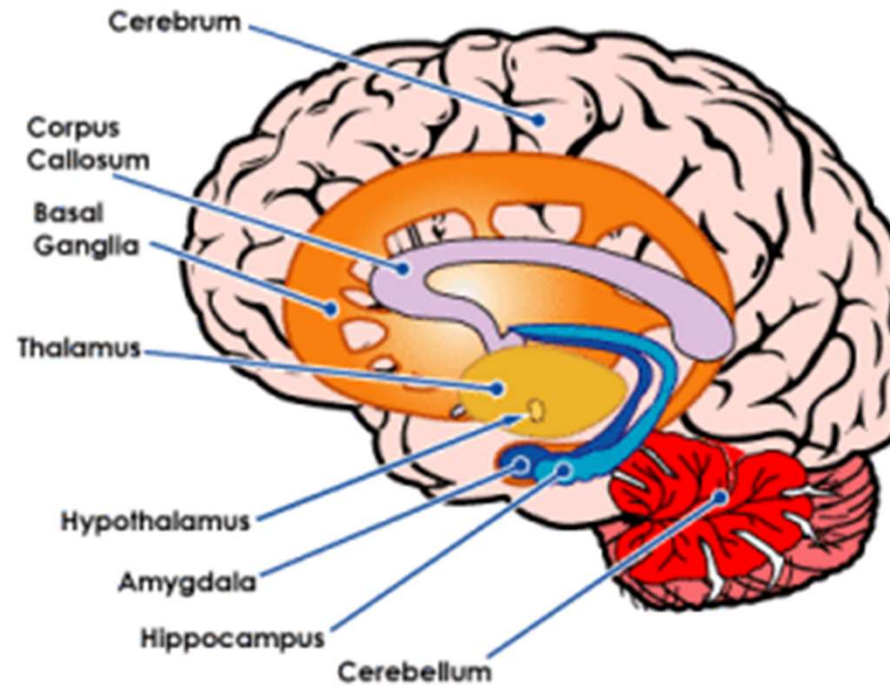
Many people have a pre-conceived idea of what Tourette Syndrome (TS) is.

You may be surprised when you watch this video to learn the truth about the many different elements of TS.



This is Gilles de la Tourette. He was a French Neurologist who first discovered this neurological condition that caused people to tic.

Basal Ganglia and Limbic System



No one knows how TS is caused or how to prevent it, but research does point to differences in the Basal Ganglia at the base of the brain. Almost all cases of Tourette Syndrome result from a variety of genetic and environmental factors, and not changes in a single gene.

Everyone's brain is unique and works
in different ways



What is it?

- Tourette Syndrome is a neurological condition
- People with Tourette Syndrome have involuntary **tics**
- Tics mean they may make sounds and do movements they really can't control
- You can have tics at any age

What are tics?

- Muscle movements or noises which the person can't help doing
- Tics can be fast
- They can happen again and again
- Tics can change
- People with Tourette Syndrome are not doing them on purpose

Here are some examples of common motor and vocal tics:

	Motor Tics	Vocal Tics
Simple	Eye blinking Eye rolling Grimacing (pulling faces) 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 Obscene movements or gestures (copropraxia) Repeating other people's gestures (echopraxia)	Non obscene socially inappropriate (NOSI) behaviour (e.g. remarking about a person's weight or inappropriately touching someone) Involuntary swearing (coprolalia) Repeating a sound, word or phrase (echolalia)

Hidden Tics

- Visual tics e.g. looking at shadows/counting objects
- Intrusive thoughts e.g. harming someone or themselves
- Suggestive tics e.g. overwhelming urges to follow through inappropriate suggestions
- Thought tics e.g. something we all think but kids 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 hard to switch off their regulator button

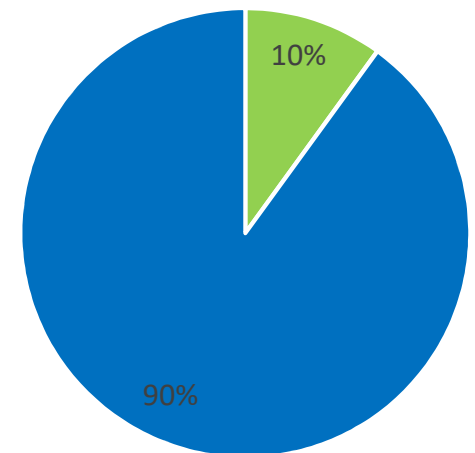
The swearing tic

This is just another type of tic - the one everyone knows about!

It's quite uncommon in children with TS.
In fact ... approximately only 10% of children with TS have it.

The name for this type of tic is “coprolalia”
(cop – row – LA – lee – ya)

We must remember that a swearing tic has no intentional meaning. Speak to an adult if you are worried by this.



■ With Coprolalia
■ Without Coprolalia


What it's not

- Tourette Syndrome is not a mental illness
- Tourette Syndrome does not affect how intelligent you are
- You can't catch it - it's not infectious


Tics **Wax** and wane

- They come and go
- They change in how severe they are
- And how often they occur


People with Tourette Syndrome are not doing their tics on purpose.



He didn't
do that last
week ...



He's doing it
all the time
now.



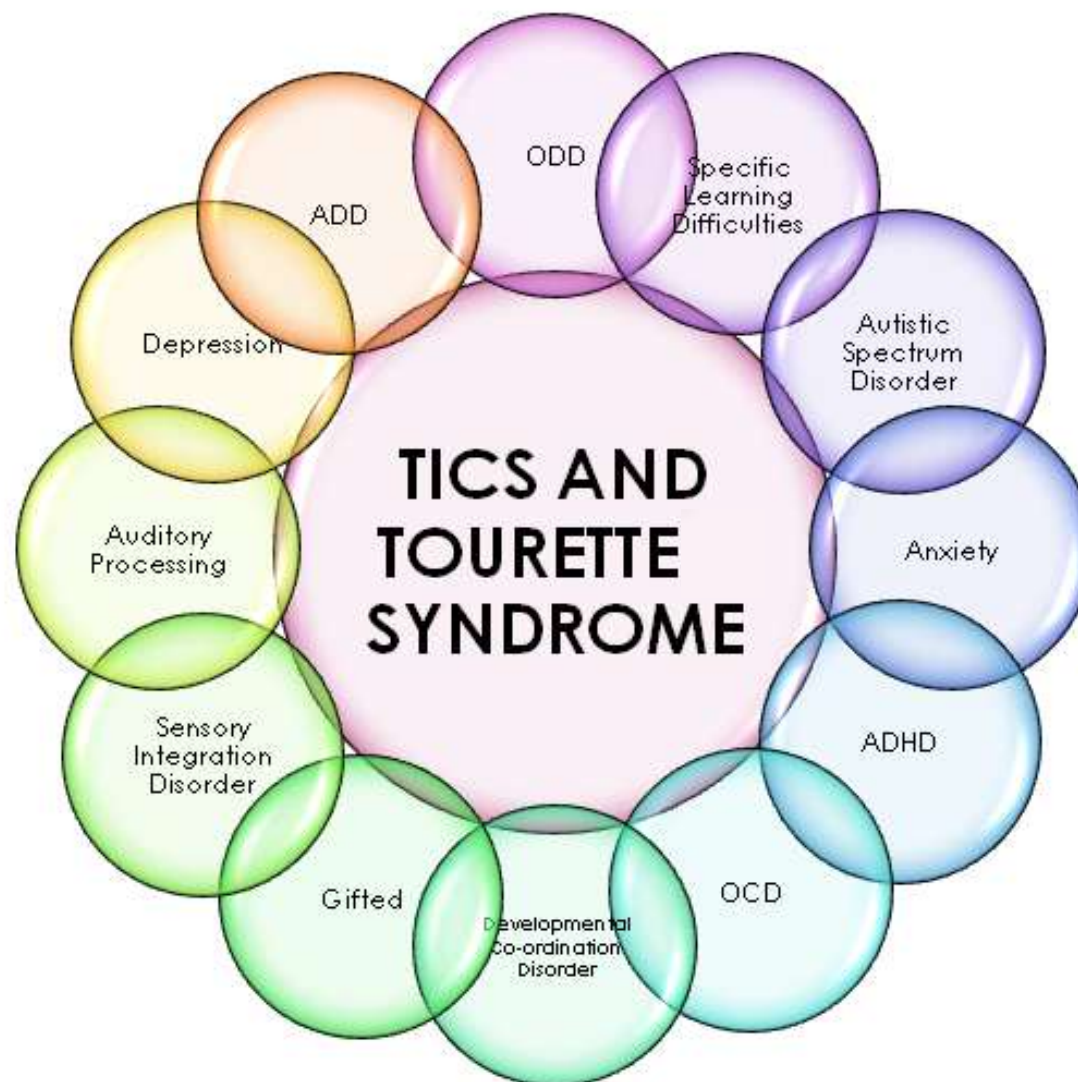
She's just
putting it
on.

Other Symptoms

People with TS often have other symptoms alongside their tics that we can't see.

One of the most common of these is worrying thoughts or the feeling that something terrible might happen. These can be very hard to explain and may need your understanding.





Some people with TS may be able to stop their tics for a short time if they concentrate really hard, but this can feel very uncomfortable.

This sometimes confuses teachers and other pupils.



Try not to blink for a whole minute and you'll see how uncomfortable this feels. This is how some children describe how it feels to hold in a tic.

*Stop doing that! It's
driving me mad!*

But I cant help it!



**We must never
ask a person with
TS to stop ticcing.**



Who has TS?

- One in every hundred school children has TS
- It occurs most commonly in boys
- TS can often reduce and in some people even completely disappear by the age of 18



*Did you know that
singer Billie Eilish
and famous
YouTuber Caspar
Lee both have TS?*



What can make tics worse

Worry, anxiety, stress, hunger, excitement, change, tiredness



What can make tics better

Exercise, distraction, deep concentration, mindfulness, sleep, routine



How can you help someone with TS?

- Learn as much about TS as you can
- Talk to them and ask them how you can help
- Be kind and understanding
- Don't tease them about their tics
- Stand up for them if they are bullied.
- Give them some time on their own if they want to release some tics in private
- Help them to join in - don't leave them out

Tourettes Action talks to Caspar Lee

Watch our video in conjunction with famous YouTuber Caspar Lee who also has TS. In this video he talks to a group of school children about their TS, how it feels and how people can help.



You are now a Tourette Syndrome expert!
You now know more about TS than most adults!
Why not test your family at home?



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Thank you!

