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Tourettes

?

ME

WHY?

Contents

Page 3– What *is* Tourettes?



Page 4– 5 facts about Tourettes

Page 5– My experience with Tourettes

Page 6– My experience with Tourettes (part 2)

Page 7- After diagnosis– My experience with Tourettes (part 3)

Page 8– What are tics?

Page 9– Where? What? Who?

Page 10– Why is it called Tourettes Syndrome?

Page 11– Symptoms and Diagnosis

Page 12 to 13– Co-occurring conditions

Page 14– Helpful links



Page 15– Afterword



Gilles de la Tourette syndrome (Tourettes) is a neurological condition (disorders that affect your brain as well as the nerves found in the human body and the spinal cord).



It is **estimated** to affect **more than 300,000 children and adults in the UK.**



Tics are a key feature of Tourettes- these are the **involuntary (do not mean to make them) and uncontrollable (can not stop them) sounds and movements people with Tourettes make.**



It usually **starts during childhood** (when you are little, around 6 or 7 years old) but the tics and other symptoms usually get better after several years and sometimes go away completely!



What is Tourettes?

1) Tourettes is three times more common in boys than in girls.

2) The sounds are called **vocal tics** and the movements are called **motor tics**.



3) The cause of Tourettes isn't known but research suggests it involves a part of the brain called the **basal ganglia (bas-al-gang-li-a)** and a **dysfunction (something is not working like it should)** of the **neurotransmitters** (little messengers in your brain telling your body what to do).

4) It was found by **Georges Gilles de la Tourette** who was French in 1885. Which makes it very old!



5) Tourette Syndrome is on the **spectrum (a scale)** of conditions known as **Tic Disorders**.

5 facts about Tourettes



My experience with Tourettes



I started “**ticcing**” around **6 years old** and it started with a **cough**. I used to cough so many times and it **made me feel shy** because I felt like I was the odd one out.

Once, **during a school play**, I was coughing and my parents could hear it which made me **feel embarrassed**.

I started to supress (**hide**) them and I still do.



I was **diagnosed** with **Tourettes** when I was **13 years old** and I was happy that I wasn't completely crazy! I was also **quite worried** as I know how some people see Tourettes.

Many people see Tourettes Syndrome (TS) sufferers as **people that swear or say rude words**– this is called **coprolalia (co-pro-la-li-a)** and this is **not true**. **Only 15-20%** of people with Tourettes have coprolalia.

I have been **looked at funny** when I say I have **Tourettes because I don't swear**. I think this needs to change.

My experience with Tourettes (part 2)



My **tics** were noticed in year 2 by my teacher. We went to the doctors but they said that it was an **allergy**.

Then I went to another doctor **and** they said the **same**. A third visit and this time they said that it was just a **habit** I had gotten into. This carried on for so many **years**. This made me feel **very** annoyed as the **doctors** would not listen.

My mum had **enough** and put her foot down (she didn't stamp that hard, so the floor was okay!) and finally, at the age of 13 I was diagnosed with **Tourettes**.

It was a long journey but it was needed.

I wonder if **you**– yes- **you**– can do me a favour? If you know anyone with Tourettes or if see anyone that you think is making a tic, ask them if they are okay. Show them that there are people out there who do care.

Tourettes (part 3)

After diagnosis: My experience with

I **was** happy that I **finally** had a diagnosis **and** that someone had **finally** listened **to** me.



I'm still **worried** about making my **tics** inside **school** because I don't **want** to draw attention **to** them. I'm also **scared** about people saying **things**.

I **think** that people **who** do suffer **from** Tourettes shouldn't **worry** about what people **will** think off them, **because** this makes their **tics** worse. The only **way** for this to happen **is** to teach more people **about** what Tourettes actually **is**.

I was wondering if **you** could teach others after you **have** finished reading **this**. If you could, that **would** be amazing!!

What are tics?

Tics are the **involuntary** (something that the person does not want to do) and **uncontrollable** (can't be controlled) sounds (could be a **cough** or a **bark**) and

They can happen in **nearly any part of the body** and in any muscle; some people talk about '**internal tics**' such as **tension in their muscles** and '**stomach tics**'.

Coprolalia (co-pro-la-li-a) is when you can't control saying bad or rude words.

Copropraxia (co-pro-pr-ax-i-a) is when you can't control making rude actions.

Echolalia (echo-la-li-a) is when you can't control copying what other people say.



Where? What? Who?



Although everyone's brain works different, my brain works in odd ways. Sometimes, it can feel like **this**



or sometimes it can feel like **this**



Most importantly, Tourettes is not a **mental** illness. You **cannot** catch Tourettes off of someone and it does **not** affect how intelligent you are. I can **stop** my tics for a short while if I concentrate, but this makes me feel tired and **uncomfortable**. **Try** not to take a breath for a **whole** minute, this is what I feel like holding my tics in. **Give** it a try! You **could** also try not to blink for **60** seconds which is impossible!

Why is it called Tourettes Syndrome?



It was named by a **French** neurologist (**neu-ro-lo-gist**)- a doctor who works with the brain- called **Jean-Martin Charcot** for his student **Georges Gilles de la Tourette**.

Dr. Tourette diagnosed **nine patients** with a “**convulsive** [when your muscles contract and feel funny] **tic disorder**.” This was the **first diagnosis of Tourettes**.



Symptoms and diagnosis

For Tourettes Syndrome to be diagnosed, you have to have **more than one motor** (ones that **don't make noise**) tics and a **vocal tic** (the ones that **make noise**) for at least a year.



Motor tics may include:

- **Eye blinking** or **eye rolling**
- **Grimacing** or making **funny faces**
- **Shrugging your shoulders**
- **Limb jerking** (**arms or legs moving violently**)

Vocal tics may included:

- **Whistling**
- **Clearing your throat**
- **Sniffing**
- **Coughing**
- **Grunting**
- **Animal sounds** (not just moo or baa!)



There are also **complex** (many tics in one) tics that include **spinning around**, **coprolalia**, **jumping** and **twirling**.

Co-occurring conditions

There are many **co-occurring conditions** (things that happen along with TS). These include:



Attention Deficit Hyperactivity Disorder (ADHD): finding it hard to **pay attention** (inattentiveness) **hyperactivity** (unusually active) and **impulsiveness** (doing things randomly) that **interferes** (stops things happening properly) with **functioning or development**

Obsessive Compulsive Disorder (OCD): When some one feels they **have to do certain things** in certain ways or at **certain times**.

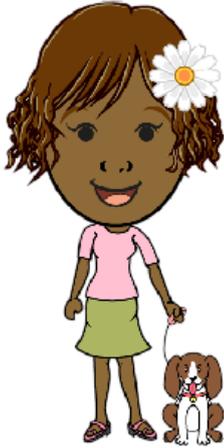
Anxiety: unpleasant (not nice) **feeling of tension** and worry **constantly**– even while doing day-to-day things.



Anger: Disruptive or angry behaviours are reported **in over 40% of people with TS**.

Co-occurring conditions continued...

Autism: this affects how a **person communicates with and interacts with other people**, and how they **experience** and interact with the world around them.



Sleep problems: may not be able to **when they are supposed to** and may have trouble with staying asleep.



There are also a couple of others such as **depression** and your **senses having difficulties processing information**– this could mean that something was **too hot but your body does not recognise this**.



Helpful links

Websites

Tourettes **Action**- [Tourettes Action \(tourettes-action.org.uk\)](http://TourettesAction.org.uk)

Tourettes**hero** (with **safe** mode)- [Touretteshero](http://Touretteshero.com)

NHS (Tourettes **Syndrome**)- [Tourette's syndrome - NHS \(www.nhs.uk\)](http://www.nhs.uk)

Books



'Why Do You Do That?: A Book About Tourette Syndrome for Children and Young People'- [Why Do You Do That?: A Book about Tourette Syndrome for Children and Young People: Amazon.co.uk: Uttom Chowdhury and Mary Robertson: 9781843103950: Books](http://Amazon.co.uk)

'Can I tell you about Tourette Syndrome?: A guide for friends, family and professionals'- [Can I tell you about Tourette Syndrome?: A guide for friends, family and professionals: Amazon.co.uk: Mal Leicester: 9781849054072: Books](http://Amazon.co.uk)

'Kids in the Syndrome Mix of ADHD, LD, Autism Spectrum, Tourette's, Anxiety, and More!: The one-stop guide for parents, teachers, and other professionals'- [Kids in the Syndrome Mix of ADHD, LD, Autism Spectrum, Tourette's, Anxiety, and More!: The one-stop guide for parents, teachers, and other professionals: Amazon.co.uk: Martin L. Kutscher, MD With contributions from Tony Attwood, PhD and Robert R. Wolff, MD: 0884384718429: Books](http://Amazon.co.uk)

Afterword

Thankyou for taking the time to read this. I hope **you** have learned something **new**.

I put this booklet together to raise awareness of Tourettes, and yes, I am still learning new things everyday.



If you ever see anyone ticcing, remember to be respectful. Although it may seem funny to watch, try and put yourself in the sufferers shoes. **Don't** stare, and don't ask "**What is wrong with you**". **Ask** the person politely if they are o.k. They may just appreciate this.

Please never **make** fun of someone with **Tourettes** Syndrome. Chances are it will probably not be the first time they have been made fun of, and just remember, it is not nice.

I hope **you** will teach others **about** Tourette's **Syndrome** – and tell people that swearing tics do **not** happen a lot!

