



Tourette Syndrome Advice Sheet—What is Tourette's?

What is Tourette's?

Tourette's is far more than the image you are likely to see in the media. In the media, it is sensationalised and portrayed to be all about the 'swearing' which leads to people feeling it's ok to laugh and mock those living with Tourette's. This is NOT Ok and we are working hard to change people's perception.

Let's dispel the myths and burst the stereotypical image.

Here are the facts around Tourette Syndrome:

Tourette Syndrome (TS) is a complex, neurological condition that is as common as 1:100 people.

Tics are the main component of TS. These are **involuntary** movements and verbal sounds, words and phrases which are not a reflection of that person's thoughts, feelings, or an insight into their inner world.

What is NOT commonly understood about TS, is that it often doesn't come on its own. Most people who have a TS diagnosis also have other complex conditions to cope with as well, such as ADHD, OCD, Anxiety and Autism, to name a few.

What are Tics?

Tics are completely **involuntary** and people with TS have no control over them.

Some tics are consistent and that means you will see them all the time. They are often painful and cause fatigue. Imagine you have a repetitive strain injury; you can rest and adapt what you're doing to allow the sore area to heal. As tics are **involuntary**, even when they are causing pain and fatigue, the person with TS cannot control or stop them.

Some tics are transient, which means they come and go and are unpredictable, often causing embarrassment and difficult situations for people with TS.

Some tics are contextual or environmental, meaning that something in the environment can trigger the tic. Examples of this would be shouting "BOMB" at an airport, making pig noises when they see a policeman, slapping a bald man's head or pushing the emergency button/fire alarms.

There are different types of tic. Here are some examples:

Motor: These can be eye-blinking, neck and head jerks, arm and leg movements, pinching, kicking, hitting, freezing position, taking clothes off, falling to the ground, etc.

Vocal: These can be throat clearing, grunting, sniffing, coughing, repeating words and phrases, animal sounds, different accents, stuttering, singing, breathing tics, etc.

Unfortunately, there are some more complex tics called Coprolalia and Copropraxia:

Coprolalia: Only 10% of the Tourette's population have these tics and they are quite often linked to contextual/environmental tics. Examples of coprolalia could be shouting something racial when you see someone with a different skin colour. It might also be something homophobic, sexual or regarding disability.

Copropraxia: Includes offensive hand gestures, invading people's personal space, inappropriate touching of self and others, spitting and hugging and kissing others.

Please remember, these are not a reflection of what the person with TS thinks or feels, nor are they directed at you—they are involuntary.

What are the Triggers for Tics?

Tics can be triggered by anything at all. Stress, anxiety and sensory overload are very common triggers. We've already mentioned environmental triggers. There are also other triggers, such as feeling nervous, not knowing what's happening next, what the expectations are as well as confrontation.

What is Suppression?

People with TS can sometimes suppress tics for a short period of time but this cannot be maintained as it takes a huge amount of concentration. Suppressing is also exhausting and can be painful and it interferes with the person's ability to cope with everyday experiences. As a result of suppressing, people with TS may be easily agitated, feel short tempered, have a lack of focus or it can bring on Tic Attacks. Imagine trying to hold in a sneeze all day—it takes a lot of effort and it still has to come out at some point where it's usually louder and more noticeable.

How can you help?

- Remember, tics are not directed at you.
- Try not to stare—tics are embarrassing and when people stare it makes them worse and makes the person with TS feel very anxious.
- Try to ignore tics.
- Everyone with TS is different and everyone has their own way of dealing with tics—it's ok to ask how they would like you to react. Some people prefer you to ignore their tics, others prefer to deal with their tics using humour.
- If someone looks like they are having a difficult time with their tics, it's ok to check in with them and offer reassurance.
- Please be understanding.
- Please be patient.

Finally, our one wish is for people with TS to feel comfortable being out in their communities, either on their own or with friends and family. Often people with TS choose to isolate or are too anxious to leave their homes because of bad experiences with people's reactions to their tics. Please be kind and remember the courage it has taken for that person to be out and about and, if you see someone having a difficult time, a kind word goes a long way.