

Tourette Syndrome Awareness Month

Each slide has a turquoise background with small purple polka dots. The LUNA logo is in the bottom right hand corner. The text for each slide is in a light blue text box. The title of each slide is written in orange and the rest of the content is written in black.

Slide 1

The first slide has a turquoise background with small purple polka dots. The LUNA logo is at the top of the slide in the centre. There is text that says "Tourette Syndrome (TS) Awareness Month" and TUR·RET SIN·DROWM in an orange font.

Slide 2- What is Tourette Syndrome?

Tourette Syndrome (TS) is an inherited neurological condition. The main components of TS are Tics.

These are involuntary movements and verbal sounds, words and phrases which are not a reflection of that person's thoughts, feelings, or insight into their inner world. Tics can occur in nearly any part of the body and in any muscle. Tics are completely involuntary and people with TS have no control over them.

Some tics are consistent and you will see them all the time but some tics are transient- meaning they come and go and are even more unpredictable. Tic patterns can also be influenced by environmental factors including stress, excitement, and relaxation.

It is estimated that 1 in 100 people are born with TS, although many of these people will never be diagnosed as it's likely they will have tics so mild that they may not even be aware of them.

Slide 3- Types of Tics

- Motor: this can include eye-blinking, neck and head jerks, arm and leg movements, pinching, kicking, hitting, freezing position, taking clothes off, falling to the ground, etc.
- Vocal: this could be throat clearing, grunting, sniffing, coughing, repeating words or phrases, animal sounds, different accents, stuttering, singing, breathing tics, etc.
- 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 swearing or shouting something inappropriate.
- Copropraxia: Includes offensive hand gestures, invading people's personal space, inappropriate touching of self or others, spitting, and hugging and kissing others.

Slide 4- Premonitory Sensations

Many people experience a physical sensation, a premonitory urge before they express a tic. This premonitory sensation has been compared to other physical sensations such as the need to itch or sneeze.

Suppressing a tic can increase the premonitory urge, and once a tic has been performed the premonitory urge often reduces. For some people, multiple attempts of a tic are necessary until it 'feels just right' and the premonitory urge goes away.

Examples of premonitory sensations include:

- a burning feeling in the eyes before blinking
- a dry or sore throat before grunting
- an itchy joint or muscle before jerking

Slide 5- Can Tics Be Controlled?

Although tics are involuntary, some people with TS are able to suppress their tics for a short time. However, this is not recommended as it takes both a huge amount of concentration and energy. Suppressing tics can also be painful, interfere with a person's ability to cope with everyday experiences and could trigger a tic attack.

A helpful way of understanding this is to compare it to blinking. For a short period of time it is possible to keep your eyes wide open and avoid blinking – and with practice you will get better at doing it for longer – but eventually you will have to blink as the urge is too strong to control. Suppressing tics works in the same way.

It is important that we remember that some people will be able to suppress their tics more easily than others and that people with TS should not be expected to suppress.

Slide 6- Coexisting Conditions

Something that is not commonly understood about TS is that it rarely occurs alone.

Many people who have a TS diagnosis also have other complex conditions.

Some of the most common examples of these coexisting conditions include: ADHD, OCD, Anxiety, ASD and SPD to name a few.

Tourette Syndrome and the coexisting conditions mentioned are all forms of neurodiversity. This term is used to describe the range of differences in individual brain function and behavioural traits, regarded as part of normal variation in the human population.

Slide 7- Supporting a friend with TS

- Remember, tics are not directed at you!
- Don't stare - people with TS can sometimes find their tics embarrassing and when people stare it makes them worse and can cause a huge amount of anxiety.
- 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 them by 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.
- Be understanding.
- Be patient.

Slide 8

Like every chronic condition TS exists on a spectrum of severities. Each person with TS will be impacted differently by the condition. What tics they have, what they are triggered by and how they manage their condition will be unique to each person, as well as being somewhat variable day to day.

The nature of TS also exists on a fluctuating scale so a person's presentation may differ from one day to the next based on many factors including environment, sleep and stress. It is therefore important to be mindful of this when supporting someone with TS- be adaptable and keep an open dialogue.

Slide 9- Challenge the Stigma

Tourette Syndrome is a condition that bears a lot of stigma and misunderstanding - often being generalised as the condition that causes people to intentionally swear a lot or say rude things. (As mentioned earlier tics are involuntary and whilst some people with TS do experience Coprolalia tics (swearing) this is a small number).

This stigma is so often perpetuated by celebrities, most notably comedians who seem to make a habit of placing TS as the punchline of their jokes.

So it is our duty as informed individuals to challenge those making inappropriate comments about TS, call out comedians making ableist jokes and help in destigmatising the condition.

Slide 10- Find out more:

There is a photo of each of the following 4 people as well their name and instagram handles.

There is also a picture of the logo for 2 TS organisations.

These are:

- Tourette Scotland
- Cece @otters.have.pockets
- Evie Meg @thistrippyhippie on TikTok
- Neve @neveticalot
- Paul @paul_stevenson_official
- Tourettes Action