

Tourette Syndrome National Awareness Week
3-9th May, 2015

Tourettes

#I'm just like you

PRESS RELEASE 2015

Awareness week is intended to make us **stop, think** and **understand** more about Tourette Syndrome.

Tourette Syndrome (TS) is a neurological disorder for which there is no known cure. Awareness, understanding and acceptance are our key strategies to improve the quality of life for those with TS.

TSAA is the only organisation in Australia committed to supporting people effected by Tourette Syndrome. TSAA is a volunteer, self funded registered charity. After 26 years of campaigning and spreading awareness most people in the community have now heard the term Tourettes—but few have a true understanding of what it means.

#I'M JUST LIKE YOU CAMPAIGN

To give an inside view, TSAA created a 3 minute video with children and families affected by TS while attending an annual camp. The input of the children themselves determined the content—from their perspective and personal experiences.

THE CHALLENGE IS SIMPLE

- ✓ [Watch the video via this link](#)
- ✓ Post the video
- ✓ Change your status on FaceBook or other to a (tic) ✓
- ✓ Nominate 10 people to change their status

When sharing the video, use # (handlers) to cross/align messaging with relevant topics expressed in the video:

#imjustlikeyou
#withtics
#tsaa
#tourettesyndrome

WHAT TOURETTES IS NOT

- #1: Tourettes is NOT bad behaviour, or swearing, or 'put on'— it is neurological
- #2: Tourettes is NOT rare—A little known fact is TS affects 1% of the childhood population
- #3: Tourettes is NOT just tics—Over 80% of people have co-morbid or associated conditions, such as ADHD, OCD and anxiety
- #4: Tourettes does NOT affect intelligence—People with TS are just as smart as the general population
- #5: Tourettes is NOT catching it is genetic—we have done nothing wrong to have it
- #6: TS is NOT simply involuntary swearing. Some people have more severe symptoms than others and fewer than 15% of people with TS exhibit this form of vocal tic

FURTHER INFORMATION AND MEDIA ENQUIRIES

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Tourette Syndrome Association of Australia Inc.



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SO WHAT IS TOURETTES?

Tourette Syndrome (TS) is a neurological disorder with no known cure. It is characterised by a combination of chronic muscular tics (twitch-like movements) and vocal tics (involuntary noises).

Tics are involuntary, rapid, repetitive movements of individual muscle groups. A tic has been described as an irresistible urge to scratch an itch or an uncontrollable need to sneeze. It cannot be held onto and must be released.

Tourette Syndrome is characterised by multiform, frequently changing motor and phonic tics. Tics may be transient lasting only a few weeks or a few months. Tics tend to come in bursts or "bouts". A bout of ticcing may be followed by a period of calm, and then another bout of ticcing. These periods are called waxing and waning cycles.

It is believed TS stems from the abnormal metabolism of brain chemicals (neurotransmitters). Basically the brain is over stimulated with an excess of neurotransmitters that bypass the filters in the brain which would normally be used to control one's movement, thoughts, emotions and actions.

TS usually starts in childhood and is likely to persist throughout life in varying degrees of severity.

There is a wide range of severity in tics that people diagnosed with TS experience. Some tics are so mild that they may be undetected by people in close contact with the person while other challenges of TS can include any combination of compulsive obsessive thoughts and behaviours (OCD), lack of attention (ADHD/ADD), anxiety, depression, sleep disfunction and learning difficulties.

REACTION AFTER DIAGNOSIS

Hearing a diagnosis of Tourette Syndrome may not produce the initial dismay one might expect in a parent or individual. Often this diagnosis comes as a relief after months or years of experiencing tics and behaviours that are hard to understand. The relief is usually short-lived as the implications of having this disorder emerge. Generally at the time a person is diagnosed, those around them do not know or fully understand the condition and it is normal to feel shocked and fearful of what may lie ahead. It is therefore not usual to experience a roller coaster of emotions when hearing of a diagnosis of TS.

THE IMPORTANCE OF UNDERSTANDING TS

Though TS has clinical similarities for most individuals, the profile, response and adaptation to living with the disorder can vary enormously depending on many things. The most important of these is how others perceive the person with TS and this is where having the correct information, about what initially can appear a baffling disorder, is so vital. When people are armed with information about Tourette Syndrome, the easier it is for carers and educators in particular, as well as the general public, to empathise and respect individuals with TS.

Some of the many things that affect the way TS will manifest in any individual are:

Age at diagnosis – The age at which TS is diagnosed is important, in that the earlier the understanding, the better the long term outcome. Diagnosis is one of the best 'treatments'; as understanding the disorder can buffer reactive emotions to it. In many cases, misunderstanding or

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lack of diagnosis can lead to depression, anger, frustration and anxiety, all of which make things worse, as one struggles to contend with symptoms that are unexplainable and disruptive.

Children diagnosed early, if educated on the disorder and how it may affect them, often develop resilience as they grow with the knowledge of their condition. They are less likely to become isolated or fall prey to teasing and ridicule from peers if they can explain what having TS means. This is a skill that takes practice but will aid them through life, as TS is a lifelong condition.

Severity of symptoms – TS is a spectrum disorder and symptom expression can vary widely from very mild tics and behaviours right through to tics so severe that they disrupt the activities of daily living. This is a complex and individual condition. Additionally, comorbidities such as ADHD or OCD further complicate the picture. For many people, identifying the most disruptive aspect, whether it be the tics, or attentional problems, or anxiety/obsessive compulsive behaviours, is an important step to getting the right help.

Acceptance – The first place acceptance is needed is at home. The family provides the first significant support system for a person diagnosed with TS. Education of the family in understanding the disorder is imperative. A person with TS needs a place to express symptoms, to escape from observation by the wider community and to feel safe. The person with TS needs to comprehend their own needs and how TS affects their behaviour. They can then educate others and tell people on a need-to-know basis. Having TS is no shame; one simply has it and should not feel ashamed or guilty. Managing behaviour becomes much more likely if the person understands the condition and finds acceptance.

Understanding the true nature of Tourette Syndrome will lead to better acceptance of the people managing this disorder within the broader community. Given that there is no known cure, acceptance is a key factor in the overall wellbeing of a person with TS.

Robyn Latimer, president of Tourette Syndrome Association of Australia says, "People with TS are often different in a wonderful, energetic, quirky and enthusiastic way. If accepted and supported within society, people with TS can find their place and lead fulfilling lives. Our aim at TSAA is to break down negative stereotypes and help each person find understanding and acceptance in the broader community".

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