

TOURETTE SYNDROME

TOOLS FOR FIRST RESPONDERS

LEARN HOW YOUR RESPONSE CAN IMPACT LIVES

TS

TOURETTE SYNDROME
ASSOCIATION OF AUSTRALIA



TOOLS FOR FIRST RESPONDERS



UNDERSTANDING TOURETTE SYNDROME & TIC DISORDERS: THE BASICS

Tourette Syndrome is a neurological disorder characterized by rapid, repetitive, and involuntary muscle movements and vocalizations called tics and often involves behavioural difficulties..

There are two types of tics

– motor (movements) and vocal (sounds).

As seen in the chart below, tics range from head-shaking to throat-clearing.

You may see someone doing more than one tic at a time. It is important to note that you might encounter someone uttering obscenities, racial statements, or socially inappropriate phrases (coprolalia). However, only 1 in 10 individuals present this type of tic. It is also possible that you might encounter someone acting out obscene gestures (copropraxia) or even writing or drawing inappropriate words or pictures (coprographia). These tics, like all others, are involuntary.

For most people experiencing Tourette Syndrome the first symptoms usually occur between the ages of 5 and 10 years, however, some cases do emerge in individuals later in life or may not be noticed or diagnosed.

Most people with TS seem to experience their worst tic symptoms in their early teens, but tics may lessen or become more controlled as they age. However, some adults with Tourette's may still have severe or challenging tics.

The disorder does not go away after childhood.

What is TOURETTE SYNDROME?

Tourette Syndrome is a neurological disorder characterised by rapid, repetitive, and involuntary muscle movements and vocalisations called tics

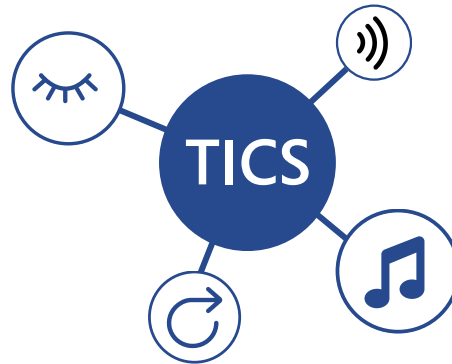
MOTOR

SIMPLE

Blinking, Nodding,
Shrugging, Sniffing

COMPLEX

Twirling, Jumping
Shaking, Throwing.



VOCAL

SIMPLE

Throat clearing,
Squeaking, Gulping

COMPLEX

Repeating sounds
or words, Whistling,
Humming

MYTH

TOURETTE SYNDROME IS CHARACTERISED BY SWEARING.

TICS ARE CONTROLLABLE

TOURETTE SYNDROME IS JUST TICS

TOURETTE SYNDROME CAN BE CONTROLLED WITH MEDICATION

VOCAL TICS EXPRESS WHAT IS ON YOUR MIND

YOU CAN'T DO MUCH FOR PEOPLE WITH TOURETTE SYNDROME

FACT

Coprolalia is a vocal tic affecting less than 10% of people with Tourette Syndrome. They cannot help it and it is not a choice.

Have you ever tried to hold in a sneeze? Just like the urge to sneeze, tics are involuntary. Trying to hold in a tic is tiring and the tic has to be released later

Over 80% of people with Tourette Syndrome have other conditions like ADHD, OCD, or Anxiety—it is very complex.

There is no specific medication for Tourette Syndrome. Treatment can help calm the symptoms—it is very individual

Vocal tics are not a reflection of a person's thoughts or beliefs—they can be triggered by environmental factors but are involuntary.

UNDERSTANDING CAN HELP PEOPLE WITH TOURETTE SYNDROME. YOU HAVE THE POWER TO CHANGE THE CONVERSATION.

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TOURETTE SYNDROME AND INTERACTIONS WITH FIRST RESPONDERS

Tics can increase in high-stress situations or where a person is feeling vulnerable or uncomfortable, such as being stopped by police, requiring medical attention, being engaged by security personnel or being confronted by the general public.

It is critical to be aware that an encounter with a first responder - which may be an anxiety and stress-provoking experience for some individuals- might cause someone with Tourette Syndrome (TS) to tic and exhibit more symptoms than in a calmer situation.

Behaviours associated with TS are often mistaken as actions related to drug or alcohol use and may appear strange, erratic or purposeful.

Due to this, individuals with TS are sometimes perceived as being rude, inappropriate, offensive, argumentative and disruptive.

Where possible, the majority of individuals with TS will try to inform people of their diagnosis, recognising that they may come across as suspicious. It is very difficult for those with TS to stay still and remain quiet due to the sudden movements and sounds of tics. An estimated 86% of individuals with TS also have another co-occurring condition, which may also affect how the person reacts in a situation.

You may encounter someone with TS or Tic Disorders uttering obscenities, racial statements, or socially inappropriate phrases (coprolalia). It is also possible that you may encounter someone acting out obscene gestures (copropraxia). These tics, like all others, are involuntary.

However, only 1 in 10 individuals present this type of tic. A lack of such tics does not mean a person does not have Tourette Syndrome.

First responders and officials must try to ignore the typical TS behaviours, even the swearing and anger, and not be drawn into further confrontation.

WHAT'S THE DEAL WITH SWEARING?

Coprolalia is the medical term used to describe one of the most stereotypical and socially stigmatising symptoms of Tourette Syndrome—the involuntary outburst of obscene words or socially inappropriate and derogatory remarks.

Copropraxia is a related complex motor tic involving obscene gestures, such as gestures representing obscene words or with genital references

Only a minority of individuals with Tourette syndrome experience **Coprophenomena** (coprolalia and copropraxia). Currently thought to affect less than 10% of people with Tourette Syndrome.

Coprolalia can be more than just swearing or involuntary outburst of obscene words as is often the understanding of Tourette Syndrome portrayed by media. It can also encompass making **socially inappropriate** and **derogatory remarks**. These tics can be quite challenging and upsetting both for the individual with TS and for people around them. Such tics are not a reflection of a person's thoughts or beliefs—they can be triggered by environmental factors but are involuntary (such as in the context of racial slurs).

Subvocalised coprolalia Some people with TS do not actually say inappropriate words out loud. They may not vocalise inappropriate words but instead, repeat them mentally.

While this may not be noticeable to others, it can still be a significant challenge and distressing for those individuals.

TIC CHALLENGES IN SOCIAL SITUATIONS

Disinhibition, the unintentional act of doing or saying inappropriate things, is commonly associated with Tourette syndrome

Inappropriate statements or behaviours result from an inability to control impulses linked to intrusive thoughts or socially inappropriate behaviours

An individual with TS may **not be able to stop themselves** from expressing thoughts or displaying actions that most people have the ability to control. For example, if someone who has trouble inhibiting sees a sign that says, “Don’t touch wet paint”, that person may have difficulty refraining from touching the paint.

Disinhibited actions do not necessarily involve violent thoughts but rather display socially inappropriate behaviours.

These behaviours may include being disrespectful, making inappropriate statements, having emotional outbursts, rage, and oppositional behaviours.

Disinhibited actions or tics may feel targeted, They can often reflect the current situation or environment, but this does not mean that these impulses are intentional or reflect the true beliefs of the individual with TS.

Many adults and teenagers with TS have learned ways to manage these impulses, which can help them avoid negative consequences and feel more comfortable in social situations. However, this can take work to develop and maintain and is not always possible when under additional stress. Someone who does not typically exhibit certain tics may show new or more intense tics in complex situations.

Additionally, complex tics, such as coprolalia and copropraxia, can create even more social challenges.

HIGH-RISK SITUATIONS

Certain situations can be more risky than others. When someone with TS is asked for their ID or other documents, they may make sudden movements or sounds that are unexpected. It's important to be aware of this and handle the situation with care.

If you're a first responder, it's important to use your training to protect yourself in potentially dangerous or difficult situations. One technique that can be helpful is to approach the person calmly and ask if there's anything you can do to help them.

In some cases, using clear and specific verbal commands, such as asking if the person is able to put their hands on the steering wheel, can be effective. It is important to ask if the person is **able** to follow your instructions. This can help prevent misunderstandings and allow the person to explain any medical conditions they may have that could affect their behaviour. Remember, your goal is to stay safe while also helping those in need.

When dealing with someone who has Tourette Syndrome, it's important to use techniques that can help calm them down. This includes being patient and understanding, asking the right questions, and communicating clearly. However, if the person is a danger to themselves or others, standard safety procedures should be followed. **It's important to remember the difference between danger and fear in these situations.**

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TOURETTE SYNDROME AND FIRST RESPONDERS RESEARCH SUMMARY

Research reveals only 28% of people with Tourette Syndrome (TS) describe their encounters with first responders as positive, while 39% say their experiences with first responders have been stressful. With misconceptions and misunderstandings about TS being a driving factor, the TS community are calling for more education to improve understanding and better the relationships between people with TS and first responders to ensure that harmful interactions with first responders are avoided.

New research by Tourette Syndrome Association of Australia (TSAA) reveals misconceptions about TS are rife among the general public, but worryingly this also applies to first responders such as police, paramedics, firefighters, and state emergency service workers. While first responders do an excellent job at keeping the population safe, sadly the research shows people living with TS have a shockingly different experience with 24% of people with TS having had a negative experience with a paramedic and 29% having had a negative experience with police.

The research indicates that there is still limited understanding about TS amongst the wider population too, with 49% of people in the TS community saying members of the public stare at them, while 62% say people seem unsure about how to respond to tics. Additionally, a third (32%) of Australians have made assumptions about someone exhibiting tic'ing behaviour.

The data reveals that the experiences of the TS community compared with the general population differ dramatically, with 14% of the TS community describing their experiences with first responders as traumatic, while another 14% described their experiences as shameful. This is a vast contrast to the majority of Australians (96%) who describe their overall experiences with first responders as positive.

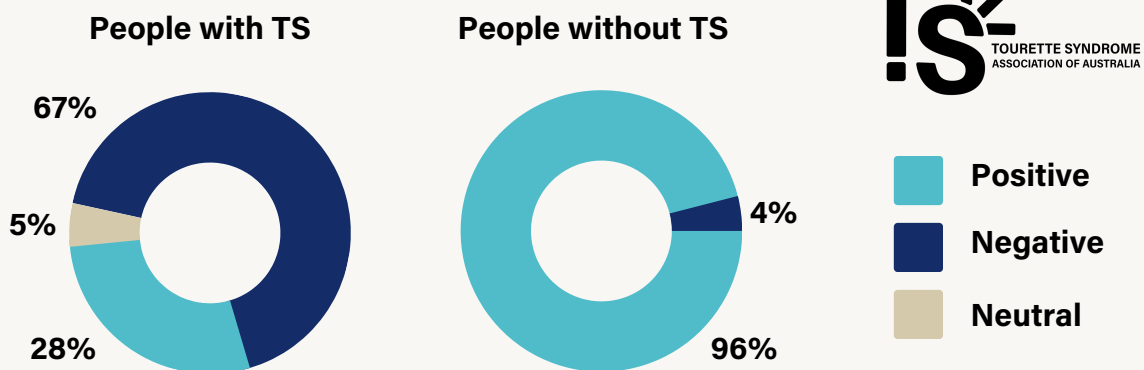
Concerningly, one in five (20%) first responders confused tic'ing behaviour with being on drugs, while almost a third (29%) confused tics with erratic or violent behaviour. Such misunderstandings regarding tics have resulted in 12% of people with TS saying they felt they were treated like a criminal for tic'ing

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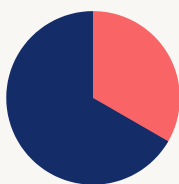


TOURETTE SYNDROME AND FIRST RESPONDERS RESEARCH SUMMARY

HOW RESPONDENTS DESCRIBE THEIR ENCOUNTERS WITH FIRST RESPONDERS



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almost a third (29%) of first responders confused tics with erratic or violent behavior.



14% of the TS community describing their experiences with first responders as traumatic



14% of the TS community described their experiences as shameful.



12% of people with TS reported feeling that they had been treated like a criminal for tic'ing

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DE-ESCALATION TECHNIQUES

When encountering someone who may be exhibiting common symptoms of Tourette Syndrome (TS), it is important to approach the situation with care and sensitivity.

Simply asking “Is there anything I can do for you?” and “Are you okay right now?” can go a long way in helping the individual feel heard and supported.

Using verbal de-escalation techniques can also be effective in increasing the individual’s compliance and reducing the likelihood of escalation.

Demonstrating patience and understanding, as well as remaining calm, are key to diffusing a confrontational situation. Law enforcement officers, in particular, should be mindful of their mannerisms and speech when interacting with someone with TS. Their approach should be calm and deliberate, with clear and reassuring speech that lets the individual know they can express themselves and that the officer is listening to them.

In stressful situations, it is critical that the individual has the ability to complete statements without interruptions. This is sometimes difficult depending on the severity of motor and vocal tics as the individual with TS attempts to communicate. By allowing them the time and space to communicate their thoughts, feelings, and needs, law enforcement officers can help reduce the level of distress and anxiety experienced by the individual with TS.

TEN DE-ESCALATION TIPS

Here are 10 de-escalation tips for first responders, officials and law enforcement officers, to keep in mind when confronting an individual with TS or Tic Disorder;

- 1** Stay calm and respectful when interacting with others to build trust and ensure cooperation.

- 2** Let the person know you're here to help since they may feel defensive when approached.

- 3** Watch for symptoms associated with TS or Tic Disorders –sudden, rapid movements and sounds.

- 4** Remember that Tics are involuntary, and the individual may or may not have the ability to temporarily suppress them.

- 5** If an individual cannot respond to an instruction, do not assume that this is because they intentionally do not wish to.

- 6** Be patient and listen to the person. Avoid pressuring them for answers, as it can exacerbate their tic. Give them time to complete their response.

- 7** Try to be understanding of the type of stress that the individual with TS may be experiencing.

- 8** First responders and officials should try to ignore the typical TS behaviours, even the swearing, obscenities, racial statements and anger, and not be drawn into further confrontation.

- 9** While tics can be confronting or concerning, if a statement or movement they are making is causing concern about whether you need to take additional actions, you may ask if it is a tic or involuntary.

- 10** Ask the right questions to obtain the necessary information to proceed and intervene appropriately. Try asking, “Is there anything I can do for you?” and “Are you okay right now?”

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DE-ESCALATION GUIDE SHEET

Watch for symptoms associated with TS or Tic Disorders - sudden, rapid movements and sounds. Remember that they are involuntary, and the individual may or may not have the ability to temporarily suppress them.

Ask the right questions to obtain the necessary information to proceed and intervene appropriately. Try asking, "Is there anything I can do for you?" and "Are you okay right now?"

Be patient and listen to the person. Avoid pressuring them for answers, as it can exacerbate their tics. Give them time to complete their response.

First responders and officials should try to ignore the typical TS behaviours such as swearing, obscenities, racial statements and anger, and not be drawn into further confrontation.

Try to be understanding of the type of stress that the individual with TS may be experiencing.

Let the person know you're here to help since they may feel defensive when approached.