



## "Psychology Works" Fact Sheet: Tourette Syndrome

### What is Tourette Syndrome (TS)?

Popular media would have families believe that Tourette Syndrome (TS) is an extreme and bizarre condition defined by swearing and outlandish symptoms. This is not at all true.

In actual fact, the average case of TS tends to be quite mild. The diagnosis requires only one phonic tic or twitch (defined as a sudden, rapid, recurrent, nonrhythmic, stereotyped sound) and two motor tics or twitches (defined as sudden, rapid, recurrent, nonrhythmic, stereotyped movements). Individuals with only motor tics or only phonic tics can be diagnosed with Chronic Tic Disorder (CTD).

Common tics include excessive, exaggerated, and or continual sniffing or throat-clearing (simple phonic tics), as well as eye blinking/widening/winking, head jerking, shoulder shrugging, or facial grimacing (simple motor tics).

In more severe cases tics can also involve more complex movements or sounds that might be misinterpreted as purposeful. Examples include repeating one's own words or actions (or imitating the actions and words of others), 'packages' of simple tics that occur together in an 'all-or-none' fashion, hopping, or unusual postures and stepping patterns.

'Coprolalia', the infamous and overly represented swearing tic, is an exceedingly rare example of a complex phonic tic. Only about 7% of individuals with TS exhibit this tic; these individuals tend to be older and with more severe and complex cases.

Symptoms don't all have to occur at the same time. Tics can change over time and they can even disappear altogether for up to three months. Once symptoms have persisted in one form or another for at least one year, the diagnosis of TS can be made. If symptoms have existed for less than one year, the appropriate diagnosis is Transient Tic Disorder (TTT).

Symptom onset is to occur before the age of 18. The average age of onset is between 5.6 and 6.4 years of age. Finally, symptoms cannot be due to a substance (e.g., medication) or a different medical condition.

### What do we know about TS?

About half of 1% of the population around the world fits criteria for TS. The prevalence is higher in males and is proportional across the normal curve of intelligence to that of the population as a whole.

In other words, while the vast majority of individuals with TS fall within the average range of intelligence, it is expected that approximately 3% of individuals with TS will be gifted, and 3% will be developmentally disabled.



Initial symptoms are typically simple, of the motor variety, and first appear in the head or facial region. Symptoms will likely occur in bursts and will wax and wane (i.e. "come and go", or increase and decrease in severity) over time and environment.

On average, tic severity peaks between the ages of 9 and 11 (Leckman et al., 2006). Most individuals continue to experience tics into adulthood but the majority of those individuals will experience significant symptom reduction by that time.

Future tic severity can be predicted by severity and degree of psychosocial stress and depression in childhood, as well as by fine motor skill deficits in childhood (Bloch et al., 2006).

Individuals can sometimes suppress (i.e. hold in) their tics for short periods of time. The ability to suppress depends upon such factors as age, cognitive functioning level, awareness of tic symptoms, and symptom severity.

Suppression of tics becomes an option because the truly involuntary aspect of most tics is the urge to tic (known as "premonitory urge") rather than the tic itself.

80-93% of individuals with tic disorders aged eight and older report premonitory sensations; evidence suggests that younger children are likely also experiencing premonitory urges but are less reliable at noticing and/or reporting them (Woods et al., 2005).

Many individuals with TS will liken this premonitory urge to an "itch" that needs to be "scratched" (by performing the tic).

Other descriptions of premonitory urges include a "tickle", sensations of warmth or pressure, or complaints of a certain area of the body not feeling "right" until the tic is performed. This need to satiate the premonitory urge increases the longer a person suppresses his/her tics, and is relieved upon releasing the tic. In this way, tics are negatively reinforced (Himle et al., 2007).

TS is a genetic disorder; however, the exact combination of genes involved is not yet fully understood. Brain imaging suggests structural and neurochemical anomalies in areas of the brain involved in motor movements; more specifically, the "stop" circuit appears to work improperly.

## **How can psychological practices be used to treat individuals with tics?**

Despite being a neurochemical disorder, there is much that psychology can offer those with tics in terms of both effective treatment and improved quality of life. Important to note is that diagnoses of TTD, CTD, and TS differ only in matter of degree (i.e. number, frequency, duration, or severity of tic symptoms). The underlying understanding and management of these symptoms does not change across diagnosis.

Punishment, Massed Negative Practice, and Suppression are not Viable Treatment Options. The ability to 'hold in' all symptoms on demand is imperfect, conscious, exhausting, and irritating. It consumes considerable internal resources, causing omission errors in other work (Woods et al., 2008). Attention, ability to focus, energy levels, social awareness, and frustration tolerance can all be negatively influenced



by suppression. Pressure from others to suppress will in all likelihood increase rather than decrease tic symptoms.

Habit-Reversal Therapy (HRT) is a form of behaviour therapy that was identified in 2007 as meeting the American Psychological Association (APA)'s criteria to be considered a 'well-established', evidence-based practice in the treatment of tic symptoms (Cook & Blacher, 2007). In HRT, a unique "competing response" is used to extinguish a target tic.

Competing responses are actions that are physically incompatible with target tics, more benign than the original symptoms, and which can be sustained for minutes at a time if necessary (until the urges pass).

Optimally, a competing response is used each time the premonitory urge arises for that particular tic, or when entering into a situation which typically elicits that tic. Using the competing response after a tic has 'escaped' is also recommended to prevent a subsequent symptom burst.

Only one tic should be targeted at a time. After an initial intense period of a few days, the target tic will decrease dramatically. Vigilance is key, as multiple spontaneous recoveries of the symptom will occur, each shorter and at a more reduced level. Over time, target symptoms can be completely extinguished from the individual's repertoire.

HRT has the advantage of avoiding significant side effects that can be associated with medications typically used to treat tics. HRT also empowers individuals with tic disorders to select which symptoms they wish to eliminate and thus to 'tailor' their own treatment.

The Comprehensive Behavioural Intervention for Tics (CBIT). In 2008 a consortium of researchers completed a multi-site, multi-million dollar study funded by the National Institute for Health (NIH) to investigate multiple behavioural treatments for tics. This flagship study combined HRT with psychoeducation, function-based intervention, relaxation training, and social support into a treatment called CBIT.

A large sample of youth aged nine to seventeen years who were diagnosed with tics and many other comorbid disorders (e.g. ADHD, OCD) were tested. Improvement in tics, and overall effect sizes obtained, were comparable to gains seen in medication trials. These significant gains were seen despite the fact that 2/3rds of the sample were already taking a medication to treat their tics, and despite the fact that the comparison group was also receiving components of the treatment (psychoeducation, social support). Most medication studies ensure that participants receive the experimental treatment alone, and control subjects receive absolutely no treatment at all, in order to maximize the effect size and statistical significance.

Psychoeducation is often the only treatment needed. Individuals with tics regularly report that reactions to their tic symptoms are more problematic than the tic symptoms themselves. Symptoms of TS can easily lead to misperceptions, ridicule, stigmatization, and social ostracization.



Proactively informing peers, teachers, parents or co-workers about TS through school assemblies or staff presentations is therefore an extremely important component of initial care; in fact, a thorough demystification can even diminish any further need for treatment at all.

Psychology can also help with neurodevelopmental conditions commonly comorbid with TS. For example, Obsessive-Compulsive Disorder (OCD) is a condition that occurs in anywhere from 28-67% of TS cases. Exposure & Response Prevention (ERP) is a highly effective treatment approach for OCD.

## Tips and t(r)ic(k)s

Two factors that are known to exacerbate tic symptoms are increased concentration on symptoms (which can result in an individual paradoxically engaging in certain symptoms at increased levels once these symptoms are suggested or his or her attention is drawn to those symptoms) and stress. Stress in this context would include eustress (e.g. excitement over an upcoming positive event) as well as distress (e.g., being hungry/tired/frustrated/hot, in a large crowd).

In preparation for the diagnostic appointment, parents are strongly advised to keep a diary of symptoms and to audio or video-record symptoms. This is because children will often suppress their tics with in the psychologist's or physician's office, which may delay proper diagnosis.

TS rarely occurs in isolation. Other neurodevelopmental conditions which commonly co-occur with TS are Attention-Deficit/Hyperactivity Disorder (ADHD), Obsessive-Compulsive Disorder (OCD), Learning Disorders, and sensory processing dysfunctions.

When an individual must contend with many or all of this dysregulation without treatment or accommodation, other problems can begin to appear (anxiety, demoralization, sleep difficulties, oppositional/defiant behaviour and intermittent explosions ('rage')).

While these secondary symptoms are often the paramount reasons for pursuing treatment, focusing on treatment of the TS and associated neurodevelopmental conditions tends to be a better treatment of these secondary symptoms than targeting them directly.

Stimulant medications do not cause tic disorders. Contrary to popular belief, stimulant medications commonly used in the treatment of ADHD (e.g. Ritalin, Concerta, Adderall, Biphentin) do not always exacerbate tic symptoms. Many individuals find their tic symptoms unchanged or even improved with the use of stimulant medication (Gadow et al., 2007). Others find that all tic exacerbations as a result of stimulant use can be reversed or decreased as a function of either dosage or stimulant used (Castellanos et al., 1997). At this time there is no definitive evidence to indicate that stimulant medications can cause the emergence of tics (Pidsosny & Virani, 2006), and a 2005 consensus statement by the Global ADHD Working Group indicated that the incidence of tics does not increase significantly in most patients when treated with stimulants (Remschmidt, 2005).



## References

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## Where do I go for more information?

For more information visit the following websites:

- The Tourette Syndrome Foundation of Canada at <http://www.tourette.ca>.
- "Life's a Twitch!" at <http://www.lifesatwitch.com>. Film available from the National Film Board at <http://www.nfb.ca>.

and

- "I Have Tourettes, but Tourettes Doesn't Have Me". Produced by Home Box Office (HBO) and the Tourette Syndrome Association (30-minute DVD).
- Tourette's Syndrome: Finding Answers & Getting Help." Mitzi Waltz.

**You can consult with a registered psychologist** to find out if psychological interventions might be of help to you. Provincial, territorial and some municipal associations of psychology often maintain referral



services. For the names and coordinates of provincial and territorial associations of psychology, go to <http://www.cpa.ca/public/whatisapsychologist/PTassociations/>.

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