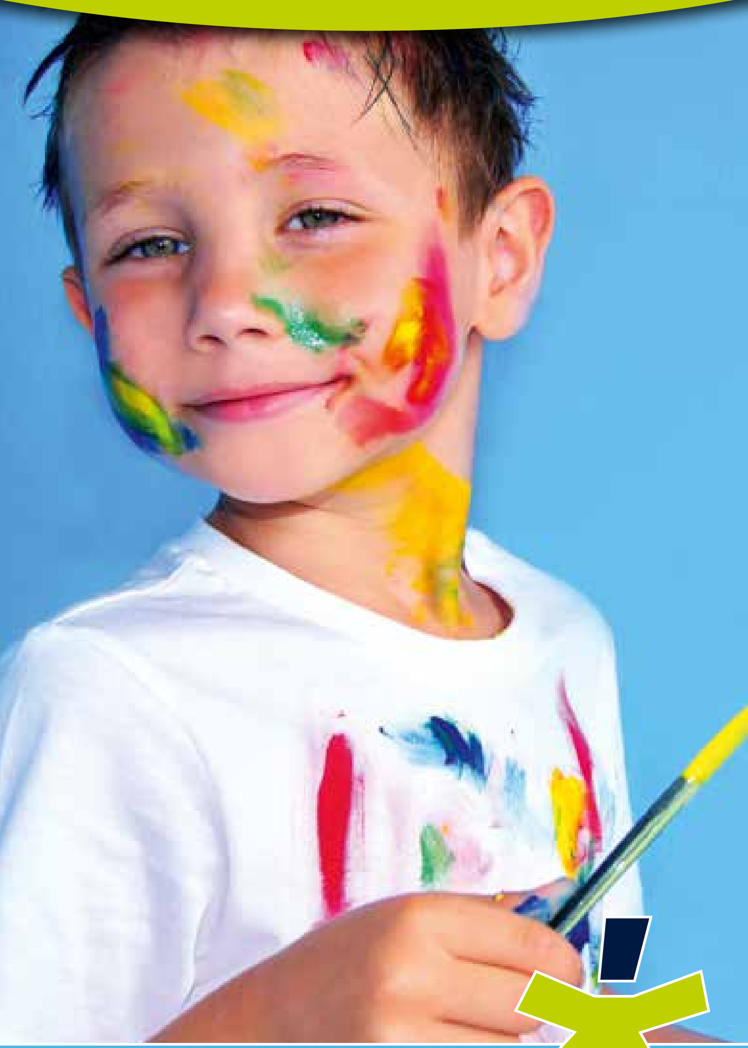
Tourettes action

Tourette Syndrome

WHAT MAKES US TIC?



www.tourettes-action.org.uk

This guide is intended as a general introduction for those recently diagnosed with Tourette Syndrome (TS). Family, friends and anyone working alongside someone with TS will also find this guide useful as it contains information for anyone taking on a caring and supportive role.

This guide will help you understand more about TS and the treatments, support and services that are available. If you'd like to talk about any of the information in this guide, please contact the Tourettes Action Helpdesk. There is also more information on our website.

Our Helpdesk is open
Monday – Friday, 9am – 3pm:

0300 777 8427
help@tourettes-action.org.uk
www.tourettes-action.org.uk

What is Tourette Syndrome?

Tourette Syndrome (TS) is an inherited neurological condition. It affects one school child in every hundred and is more common amongst boys. Over 300,000 children and adults are living with TS in the UK.

The key features are tics – involuntary sounds and movements, which must be present for at least 12 months to meet the diagnostic criteria. Over 85% of people with TS will also experience co-occurring conditions and features which might include Attention Deficit Hyperactivity Disorder (ADHD), Obsessive Compulsive Disorder (OCD), and Anxiety.

TS is often misunderstood as a condition which makes people swear, or say socially inappropriate things. Although it is true that 'coprolalia' – the clinical term for involuntary swearing – is a symptom of TS, it only affects a minority of people. 90% of people with TS do not have coprolalia.

Cause

Although the cause has not been established, it appears to involve an imbalance in the function of neurotransmitters (chemical messengers in the brain), dopamine and serotonin. It is also likely to involve abnormalities in other neurotransmitter systems of the brain.

TS is a genetic condition that often runs in families, and can occur with co-occurring conditions such as Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive Compulsive Disorder (OCD). The genetic cause of TS is complex as not one single gene has been identified to be the cause of the condition.

Brain scanning has revealed that there are some areas of the brain that appear to be different in individuals with TS, for example some structures in the basal ganglia part of the brain, and in the fronto-temporal brain areas.

Different environmental factors may, in some cases, contribute to the onset or affect the severity of TS. These include pregnancy and birth related problems such as complications during pregnancy, and premature low birth weight children.

Symptoms

Tics usually start in childhood around the age of 6–7 years and symptoms tend to peak at around 11–12 years of age. TS is a fluctuating condition which means that tics can come and go.

Tics can also be triggered, or increased by environmental factors such as stress, excitement or relaxation. TS is a spectrum disorder which means that symptoms range from mild/simple to complex.

Tics can occur in nearly any part of the body and in any muscle; some individuals report of ‘internal tics’ such as deep abdominal muscle tension and ‘stomach tics’.

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Below is an example of common motor and vocal tics:

MOTOR TICS

VOCAL TICS

SIMPLE

Vocal tics

- Whistling
- Throat clearing
- Sniffing
- Coughing
- Tongue clicking
- Grunting
- Animal sounds

Motor tics

- Eye blinking
- Eye rolling
- Grimacing (pulling faces)
- Shoulder shrugging
- Limb and head jerking/ head nodding
- Abdominal tensing

COMPLEX

Vocal tics

- Non obscene socially inappropriate (NOSI) behaviour (e.g. remarking about a person's weight or inappropriately touching someone)
- Involuntary swearing (coprolalia)
- Repeating a sound, word or phrase (echolalia)

Motor tics

- Jumping
- Twirling
- Touching objects and other people
- Obscene movements or gestures (copropraxia)
- Repeating other people's gestures (echopraxia)

Premonitory urge

Many people experience a physical sensation – a premonitory urge/tic signal – before they express a tic. It 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.

Can tics be controlled?

Although tics are involuntary, many people are able to suppress their tics for a short time. 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 can take a great measure of concentration – especially to begin with – to resist the urge to tic, but with practice a certain level of control can be applied. Some people will be able to suppress their tics more easily than others.

It is quite common for children with TS to suppress their tics at school, yet families will notice a marked increase in their child’s tics once they get home. This is likely to be a result in the change of environment. School is very structured and has reinforcers that may make a child want to control their tics. In comparison home life is more relaxed and therefore helps children to feel at ease with expressing their tics.

How should I respond to tics?

Generally speaking it is not helpful to ask someone with TS to stop their tics. Tics are involuntary and being asked to suppress them can be stressful and sometimes cause the person to tic more. Pointing out someone's tics to them, without any reason other than to highlight it can also be unhelpful and lead to increased ticcing.

Ignoring tics can help someone with TS feel comfortable, as this avoids drawing any unnecessary attention towards them. However, as a parent, a teacher or a friend, you might feel the need to talk to a person about a particular tic if it seems to be causing them distress or harm. This is OK to do, as long as it is done in a sensitive way. This is very different to highlighting a tic for no apparent reason or asking a person to simply stop.

There is a wide variety and range of tics, so some tics will be easier to ignore than others. For example, a shoulder shrugging tic may be easier to ignore than a high pitched vocal tic. In these circumstances think practically about what you can do to ensure that everyone is comfortable. For example, you might choose to wear ear plugs if you live with someone who has frequent loud vocal tics. Or if someone has an arm throwing tic, then a useful response would be to sit outside of their range to avoid accidental contact.

Coprolalia (involuntary swearing) and Non Obscene Socially Inappropriate (NOSI) behaviour (e.g. remarking about a person's weight or inappropriately touching someone) are also involuntary tics. Although it can be challenging to hear someone swear or say inappropriate things, the challenge is much greater for the person who wants to control their tics but can't. Having coprolalia and/or NOSI brings lots of unwanted attention – the very opposite to what is needed to help someone with TS feel comfortable and accepted.

In some cases a person with TS may be able to find another word or sound to replace the obscene/inappropriate word, but sometimes that's not possible. As a society we have a responsibility to help people with TS feel accepted and understood. Once we can see beyond the social taboo, it is possible to attune our listening, filter out our emotional reaction to what are otherwise empty words, and instead listen and respond with support and understanding.

Co-occurring features and conditions

Over 85 percent of people with TS will have additional symptoms to tics. Co-occurring conditions may include OCD, ADHD, Anger, Depression, Anxiety and Sleep problems. People with TS may also experience sensory processing difficulties – where they are either over-responsive or under responsive to sensory stimuli, e.g. noise, clothing, textures. These additional features and conditions can, for some people, be more challenging to live with than tics. Additional symptoms are often less visible than tics and may be easily overlooked.

Attention Deficit Hyperactivity Disorder (ADHD)

ADHD is the most common co-occurring condition with TS. ADHD is defined as a group of behavioural symptoms that include inattentiveness, hyperactivity and impulsiveness; that interferes with functioning or development.

Obsessive Compulsive Disorder (OCD)

OCD is an anxiety-related condition where a person experiences frequent obsessional thoughts and/or compulsions that cause serious distress.

Anxiety

Anxiety is an emotion which gives someone an unpleasant feeling of tension and worry. It can be triggered by a stressful event or if someone feels under threat. Anxiety is a normal emotion, however, when anxiety is persistent, interferes with normal routines, and does not go away with reassurance and comfort; it is classified as an anxiety disorder.

Anger

Disruptive or angry behaviours are reported in up to 40% of people with TS. It can be very helpful to understand what the triggers and consequences of getting angry can be when learning how to manage this behaviour. Therapists can help with identifying this and Tourettes Action has resources for parents on how to support a child with anger issues.

Depression

Depression is when someone experiences low mood for a prolonged period of time. Everyone can experience low mood from time to time – it is a normal emotion. When feelings of low mood and sadness are persistent, this might be a sign of depression.

Sleep problems

Sleep problems in people with TS can include difficulty falling asleep and frequent waking at night.

You can find more information about co-occurring conditions, including links to specialist organisations on the Tourettes Action website.

☎ **Call our Helpdesk: 0300 777 8427**

Living with Tourette Syndrome

If you do not already know someone with TS, it is likely that your only knowledge of the condition comes from the media, which typically focuses on coprolalia. Although this symptom is a reality for some people, it is only a small part of the bigger picture.

As TS is a fluctuating condition, someone may experience periods of wellness, and times which are more challenging, depending on their current symptoms. The degree to which someone manages their TS can be largely affected by the people around them. If someone has a supportive family, friends, teachers, colleagues – they are much more likely to accept their condition and feel comfortable within themselves. So anyone in a caring and supportive role can help by educating themselves about TS; in doing so they will contribute to building a supportive, understanding and inclusive world for that individual. The Tourettes Action website has lots of information and resources for families, teachers, employers and people in general about TS. Or you can contact the Helpdesk for further information.

Currently there is no technology that can predict how TS might affect someone long-term. It is thought that approximately half of children with a TS diagnosis will see a significant reduction in their symptoms as they approach adulthood. For some people, living with TS will continue throughout their life, but symptoms are likely to wax and wane (a term often used to describe the coming and going of tics), and how they manage their TS will to some extent depend on their environment. So it could be that with time a person makes progress managing their TS because they feel more secure in themselves and the people around them.

Having TS can impact on different aspects of life.

Physically

Repetitive motor tics can cause aches and pains. This can be helped with regular gentle stretching, massage and aides such as heated wheat bags which help to relax the muscles.

Physical and vocal tics can lead to tiredness, especially towards the end of the day. Having regular rest opportunities can help support energy levels.

Educationally

TS can affect concentration and tasks such as writing and reading. There are lots of strategies that can be implemented in the classroom to support a child who struggles with these activities. More information and resources about School and TS can be found on the Tourettes Action website.

Economically

Many people with TS are employed or run their own business, across a variety of sectors. Sometimes however, symptoms may prevent someone from working for a period of time or in some cases long-term. In these circumstances, individuals may be eligible for employment benefits – they will need to consult a local benefits advisor for further information. Being in work does not just depend on how active your symptoms are. Reasonable adjustments can be made in the work place to better accommodate the needs of someone with TS, helping people access and maintain employment. More information about employment and TS is on the Tourettes Action website.

Socially

TS is still a misunderstood condition by many, and there is a lot of work to be done on changing the current perception that it is all about offensive language. However, progress is being made and awareness has greatly improved over the last 10 years. Unfortunately though some people can feel socially isolated. The more we educate people about TS, the greater chance we have at de-stigmatising the condition.

Treatment

There is no known cure for TS. Treatment includes both drug and non-drug approaches; and with continued support and understanding from others, it is possible to live a fulfilling life.

Medication

Medication does not treat the underlying cause of TS but can treat some of the symptoms. There are lots of variables to consider when deciding whether drugs are a suitable treatment for an individual. Clinicians work closely with patients and their families when deciding about drug treatments. A person's age, their general health, the symptoms they present with, plus other factors– will all determine whether medication is an option, and if so, which specific drug to take.

Understandably, people can be nervous about potential side-effects of drugs. Treatments in TS usually follow the 'start low, go slow' rule (i.e. start at a low dose and increase the dose slowly). This means that side-effects, if they do occur, can be identified early on and it is easier to tell the difference between effects of the treatment and underlying changes in the TS symptoms.

Finding the right treatment is an individual process. Someone might have to try different types of drug under the supervision of their clinician, until they find one or a combination that works best for them.

Behavioural therapies

Habit Reversal Therapy (HRT)

The best scientifically validated behavioural treatment is called **Habit Reversal Therapy (HRT),** which has been researched since the 1970s. HRT can be understood in two stages. In the first stage the therapist helps a person identify their tics in detail (movements and which muscles are involved), and their awareness of when the tic is about to happen (premonitory urge). The second stage of the treatment is to find a competing response. This trains the person to perform an intentional movement, which reduces if not completely stops the tic from happening.

Comprehensive Behavioural Intervention for Tics (CBiT)

More recently, HRT has been shown to be effective as part of a package alongside other elements of therapy, known as **Comprehensive Behavioural Intervention for Tics (CBiT).** CBiT is made up of different elements including: Psychoeducation, Functional Analysis, Habit Reversal Therapy, Social Support and Reward System and Relaxation Training.

Exposure and Response Prevention (ERP)

ERP is another type of therapy that focuses on getting used to the premonitory urge (feeling before the tic). Although the full programme is similar to CBiTS in many ways, the key ingredient is about suppressing tics. During therapy, the therapist will use strategies to make the premonitory urge as strong as possible and encourage the person to get used to the feeling without doing the tic. There is evidence to suggest that this approach is as effective as CBiTS. ERP may be best suited to people who have a range of very annoying tics or are of a young age.

Accessing treatments

Behavioural therapies are delivered over a set number of sessions; this could range from 5, 10 or 10+ sessions depending on the needs of the individual. Due to small numbers of trained therapists, currently behavioural therapy services are fairly limited in the UK, although year on year more therapists are being trained to deliver this treatment. Tourettes Action holds a list of therapists who work in the NHS and privately. You can contact the Helpdesk for a copy of this list and take it to your GP or consultant to discuss referral options.

CAMHS

CAMHS stands for Child and Adolescent Mental Health Services. Often children and young people who have a diagnosis of TS will be referred to this service to receive treatment. Although TS is a neurological condition – not mental health – CAMHS can still provide treatment to support co-occurring conditions such as OCD, ADHD and Anxiety. Some CAMHS teams will also be able to deliver behavioural therapy for managing tics, because they have clinicians with an interest in tic disorders, and who have trained in this therapy.

Clinicians work closely with patients and their families when deciding about drug treatments.

Other treatments

There have been trials in the UK and internationally for treating very severe TS – which has been resistant to all other means of treatment and management – with Deep Brain Stimulation (DBS), a form of neurosurgery involving the implantation of electrodes at selected targets in the brain. The use of DBS in patients with very severe TS is still in its research stages, and although results have been hopeful, it is still not clear whether this will become an available treatment option.

There is little research evidence for not-yet-validated treatments such as acupuncture, dental braces, special diets or the use of supplements. We would always advise consulting a trusted and respected health professional before pursuing treatments that currently have no evidence base to support their use in managing TS.

A healthy lifestyle which involves regular exercise and a balanced diet promotes general well-being and helps reduce stress. Feeling good within yourself can help you cope with times when symptoms might be difficult.

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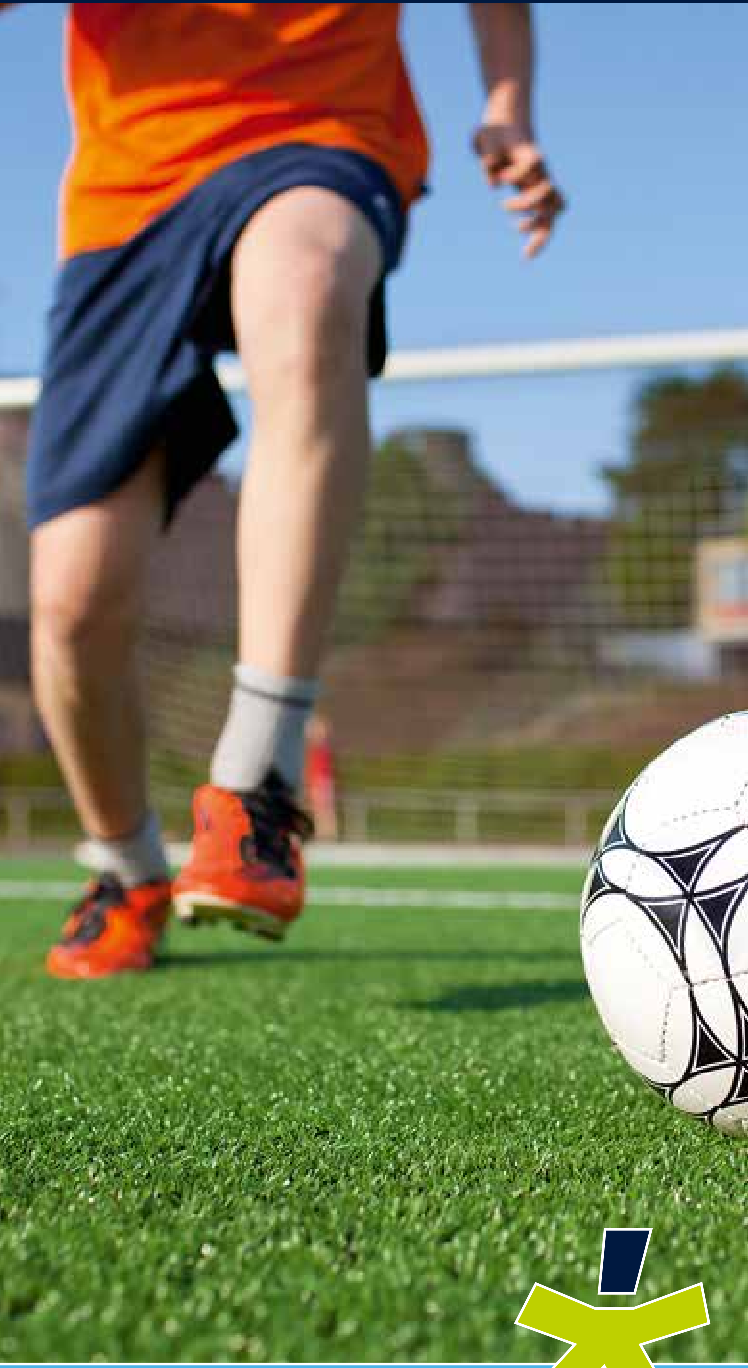

Support

If you or your child has recently been diagnosed with TS, you might be feeling sad, uncertain, alone, angry or even disbelieving. Or you may feel some relief that you now have an explanation for the symptoms you or your child has been experiencing. All of these reactions are possible at different times and they are all normal.

If it's possible, talk to friends and family about how you're feeling. Talking about things can really help to shift your emotions; and if other people understand what you're going through, they're in a better position to help you. It can also help to connect with people who have a previous understanding of TS. You can contact the Tourettes Action Helpdesk to speak with an experienced member of our team, or if you prefer you can contact us by email or through our online live chat service. Our Helpdesk is there to provide you with information and support.

Tourettes Action also offers a befriender service, where we connect individuals with trained volunteers who have experience of TS. Our befrienders offer structured 1-2-1 support by phone and/or email; they help you navigate the times when you need a familiar voice to speak with, one who understands and has been there.

It can also help to learn more about TS, this is part of the adjustment process and can help you better communicate yours or your child's needs to others. Tourettes Action works closely with leading TS specialists to develop their information and resources, all of which can be accessed from the website.

Other support services Tourettes Action provides include a grant scheme, school advocacy, and identity cards. We organise regular national and regional social events for people in the TS community, and facilitate training days for professionals.

Research

Research into genetics, brain imaging, behavioural science, neuroscience and neuropathology is helping us to make progress towards understanding the basis of TS.

One of the main aims of Tourettes Action (TA) is to support research and to seek better treatment and management of TS (via research into new therapies and potential cures) with a view to improving the lives of those living with TS.

Results from research are used to increase public understanding as well as improving the lives and health outcomes of people affected by TS.

Without research participants there would be NO research.

Without research there would be NO progress in treatments and understanding of TS.

Join up to **TA Research Participant Registry,** a voluntary database of individuals willing to consider participating in research studies or being a 'Lay reviewer' where we ask for your opinions on research proposals. This would allow TA to contact you about studies that might be of interest to you – please sign up by emailing **research@tourettes-action.org.uk.**

More information about the TA research grants, being involved as a research participant and the current studies you can be involved in are on the Tourettes Action website.

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Other resources

This leaflet is intended as an introduction to TS; there are many more resources including books, articles, videos, presentations and other leaflets which provide further information about TS. The Tourettes Action website has a resources section where you can find a wide range of information.

Tourettes Action is the UK's leading support and research charity for people with Tourette Syndrome (TS) and their families. We want people with TS to receive the practical support and social acceptance they need to help them live their lives to the full.

Call our Helpdesk to speak to us between 9am and 5pm, Monday to Friday on 0300 777 8427

E-mail us at help@tourettes-action.org.uk

Write to us at our registered office:

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Tourette Syndrome (UK) Association,
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