Tourettes action

Tourette Syndrome

an introduction

Edited by Hillary Box

November 2008

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"People need to learn that TS is involuntary. It's not our fault and TS people often have much more than just TS. We don't need pity but some will always need help, support and particularly understanding". Respondent, Online Survey 2008

Tourette Syndrome (TS) affects one adult in two thousand in the UK and one in a hundred schoolchildren. It is a complex and little understood condition. The causes and exact nature of TS have yet to be discovered.

This publication is intended as a general introduction for people recently diagnosed, for their families and colleagues, and for those who wish to know more about the condition.

Diagnosis may be a stressful time and the questions you have may be detailed and specific. For further information and support, please contact the Tourettes Action free Helpdesk on 0845 458 1252 or email help@tourettes-action.org.uk.

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What is Tourette Syndrome?

"There may be many times in life when you're asked to describe the symptoms of an illness you may have; during a visit to the doctor's, applying for a new job, even in a conversation at your local pub. You may have only a few minutes or lines to describe the symptoms – and in many cases, this is all you need. But TS goes much deeper. How do you condense into a few minutes a lifetime of varied, ever-changing tics?" Paul

Tourette Syndrome (TS) is a neurological condition of unknown origin. It is a complex condition and covers an extraordinarily wide spectrum. People may have a very mild form of TS. They and those close to them may not even be aware that they have TS. At the other end of the scale, medical symptoms are extreme and the social, educational and economic effects are serious. These are the examples of most interest to the media.

Because it covers such variation, TS is sometimes known as tic spectrum disorder.

Tics

"When my son was diagnosed with severe TS, the consultant told me that I had TS too – finally I could make sense of situations from my childhood and teenage years." Zoe

People with TS have tics which cause them to make involuntary movements and vocal noises. There are reasons for tics other than TS. Diagnosis, which is by observation, is only confirmed if both motor (movement) and vocal tics have occurred for at least a year.

Tics generally, but not always, start in childhood, often between the ages of five and seven years. Vocal tics usually start a little later than motor ones.

Tics are repetitive involuntary movements usually with a twitch-like quality, although sometimes they are slower. Tics used to be called 'habit spasms'. They can be very simple movements like winking, blinking or shoulder-shrugging; or more complex, for instance hand gestures or twirling around when walking.

Vocal tics can be similarly simple, like coughing or throat-clearing; or they may be more complex; for instance the involuntary utterance of whole words or phrases. A feature seen in many people with TS is echophenomena, repetition of words, phrases or syllables.

COPROLALIA

The well-known feature of involuntary swearing - coprolalia - is present in only about 10 percent of cases. Some people with TS also made rude gestures - copropraxia.

More recently a phenomenon known as Non-Obscene Socially Inappropriate (NOSI) behaviour has been identified where people with TS may have a compulsion to do or say the wrong thing, which may be socially unacceptable; for example, touching something they should not touch or making an insulting comment. Though inappropriate - even seemingly rude - NOSI behaviour falls short of coprolalia.

Although the word 'involuntary' is generally used to describe the unwanted sounds and movements, most people with TS can suppress their tics for a short time. This could be compared to the experience of sneezing, or trying to suppress a sneeze. Often there is a premonitory feeling or urge which is relieved by the action of ticcing. This sensation has been vividly described as like 'itchy blood', or 'insects crawling under the skin'.

"It is true that people with TS have no control over their tics but a more appropriate word than 'involuntary' would be 'compulsive'. People with TS feel an irresistible urge to perform their tics as the average person would want to scratch an itch. Some are able to suppress their tics, maybe even for hours, but this will lead to a stronger outburst once they allow themselves to tic freely." Paul

Some people are also very skilled at hiding their tics. For example, vocal tics may be disguised as coughs or throat clearing. Someone may turn aside or pretend to pick up something from the floor to conceal a motor tic. Colleagues and friends might have no idea the person has TS. Disguising tics involves huge, conscious, constant and energy-sapping effort. It may also make diagnosis difficult.

"I performed many plays, up to an hour in length, without ticcing once. Of course afterwards I was like an alarm clock on speed, but it was worth it." Francesca

Stress or boredom often makes tics worse. When someone is absorbed in a task, for example sport or music, their tics may improve. They tend to wax and wane in severity over various time periods.

"I noticed that my tics were worse when I was on my own. I think loneliness makes my tics worse." Jimmy

Comorbidities

Only about 12 percent of patients seen in clinics have a syndrome consisting only of tics. The rest have additional conditions ('co-morbidities'), most commonly obsessive compulsive disorder (OCD) and/or attention deficit hyperactivity disorder (ADHD). Children and adults may suffer from 'rages' with little provocation and usually followed by remorse. Co-morbidities often present more practical problems than the tics, and can be less visible.

The challenges of living with Tourette Syndrome

"Tics always make us feel different, tics always make us feel stressed in public, tics make it difficult for us to meet new friends and tics make it hard for us to feel confident when dealing with new things." Justin

"TS gives big gifts to me and I feel pleased to use them." Justin

People with TS have the same range of IQ as the rest of the population, with some subtle differences. There is a tendency towards lower verbal IQ (intelligence that depends on verbal reasoning using language) in relation to performance IQ (puzzle solving, mathematics, for example).

TS is very variable in its severity and co-morbidities.

Some people with TS have symptoms that are only mildly troubling. Others have symptoms that are intensely disabling:

- physically (tics can cause damage to joints or self-injury, eg hitting oneself)
- educationally (TS can make it impossible to follow what is going on in class)
- economically (TS can be a barrier to employment)
- socially (TS can lead to ridicule, bullying and social exclusion)

The main challenges are:

The core features of TS: involuntary movements and noises

Tics can be physically disabling.

Annie, 9, has a leg tic which causes her to crumple to the floor*

"As I get older, the strain on my body is starting to show." Ed, 34*

"My head tic has given me a prolapsed disc and spine problems" John, 48*

Tics may also cause damage to property and social problems.

Femi jumps up and down obsessively on his bedroom floor. He will eventually weaken it to the point of collapse and he will go through into the room below.*

For the 10 per cent of people with TS who have coprolalia, using obscene language can be very socially disabling and occasionally physically disabling.

Ethan, 8, is otherwise doing well at school but his coprolalia means parents of other children demand his exclusion.*

Features associated with TS: OCD, ADHD etc

These can be more challenging than the tics, especially for schoolchildren.

Joy is unable to produce written work because she is obsessed with perfecting a particular letter.*

Ben, 12, takes 15 minutes to enter the house due to rituals.*

Other common features

These include depression and disturbed sleep.

Medical treatment with drugs can be helpful for these features, but the effects are variable. For many people, medication is not particularly effective. Alternatives to drug therapy are not readily available. Access to expert clinical psychologists is severely restricted in the UK.

Inclusion

It is very difficult for children to achieve their full potential at school.

In the best scenario, the school is supportive and allows the child to leave lessons to tic in private, if they are embarrassed about ticcing in class. However, cumulatively, the child misses out on education.

In the worse cases, the school is not supportive, punishes child for tics and does nothing to prevent bullying. The child refuses to go to school and the parents are threatened with legal proceedings.

"the teachers keep telling him to stop making noises" … "school won't take him on class trip" … "facing expulsion/exclusion if he cannot attend college" … "school told [mother] that she will not find any schools that accept children with TS" … " a lot of problems in school with bullying, it has been one child after another"

For a number of the worst affected adults, participating in society and the workplace is a major problem.

"I had spent the last two months on a 'rehabilitation' programme after spending nine months before that on enforced sick leave. I was 'disruptive' according to my supervisor." Paul

There is also anecdotal evidence of self-exclusion.

Chris, otherwise prosperous and successful, walks out of a restaurant because it cannot offer a seat in a corner where his tics cannot be seen.*

Ali, a teenager decides not to go out with his friends one day because his tics are so bad.*

Danny, mid-30s, is good looking and a talented musician, but has never had a relationship.*

There is even evidence of rejection by families.

Mary, diagnosed at 62 has been unable to persuade her family that she is not 'putting it on'.*

Failure from statutory services

People with TS may not get support from statutory services.

"I had been fighting for a diagnosis of my 'nervous twitch' since I was 16 – my GP was unaware that TS was a possible cause." Ruth

GPs may fail to diagnose TS or fail to refer the patient to a competent specialist.

Some schools adopt a punitive approach.

Jacob spent 90 per cent of time out of class due to swearing.*

Social services have threatened parents with parenting classes and/or taking their children into care.

The doctor suggested that Andrew doesn't have TS and that his mother is 'coaching' him to tic. She's afraid he might be taken into care.*

How common is TS?

There have now been many studies on TS. Taken together, they indicate that one schoolchild in 100 has TS. Boys are affected two to four times more commonly than girls. TS is significantly more common in special educational needs (SEN) environments.

Using available figures, the number of people with diagnosable TS in the UK is thought to be between 200,000 and 330,000. The majority of them probably have a mild disorder of little medical significance, especially in adulthood. We do not have reliable figures for the number of adults whose TS impairs their day to day life to a significant degree.

TS is probably less common in adults than in children, and for most adults symptoms become less severe. On average, symptoms peak at age 11 (when many children face the additional disruption of moving school), although there is great variation. Towards the end of adolescence, about half of teenagers with TS find that their symptoms have effectively disappeared or that they are no longer significant.

Some people with TS have a severe disorder persisting into adulthood. Although the tics may improve, in some instances co-morbidities may persist or even get worse. The presence of more severe OCD is actually predictive of worse tics at a later age. However, we do not have good tools to predict whether an individual child with TS will become an adult with TS.

HISTORY

TS is named after Dr George Gilles de la Tourette, the French neurologist who first reported the condition in medical literature in 1885. For over eighty years TS was felt to be a rare curiosity. Coprolalia was traditionally considered an important element and that earned TS a place as a footnote.

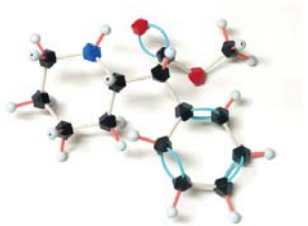
TS was believed to be a psychiatric syndrome. For example, tics were thought by some to be the result of repressing masturbation. Treatment was psychological, and included what would now be considered outlandish Freudian approaches.

From the 1970s, there was renewed interest in TS, beginning with the work of Arthur and Elaine Shapiro in New York. This and subsequent studies meant a more rounded view of TS emerged. By the 1980s, there was general agreement amongst researchers that one person in 2000 has TS.

Causes

Some doctors still think of TS as a psychological condition. In fact and without doubt, TS is a neurological disorder, due to a disturbance of underlying brain function.

Genetics



From the 1980s it became increasingly apparent that TS is mainly a genetic (inherited) condition. There were documented cases of large families where many members had TS. Consultants became aware that most of the cases of TS they saw in clinics were hereditary. Such cases are not always easy to identify. Some very mild features, such as a parent with mild obsessive tendencies, may be related to the same genetic cause. In most cases there is a more compelling family history than this, such as a parent or second degree relative with tics. Sometimes, the tics are mild enough not to have been previously noted and have only been identified when researchers interviewed extended families. So there is considerable evidence that TS is a genetic disorder with a wide range of severity.

"I was diagnosed in my thirties with TS, Attention Deficit Disorder (ADD) and Obsessive Compulsive Disorder (OCD). By this time, I had three children – in fact my diagnosis followed that of my nine-year old son's. Four years later, my older daughter was also diagnosed with TS." Zoe

Unlike many other genetic neurological conditions and despite a committed research effort largely co-ordinated by the US Tourette Syndrome Association Inc., the major genes causing TS have yet to be identified. There are many possible reasons. Multiple genes rather than a single gene may be involved. In addition, there may be more than one kind of TS, each caused by different genetic factors.

Parents with TS have a 50 percent chance of passing the gene to each child, but the pattern of inheritance is unclear. Half those children with the gene will show signs of TS, and many of them will have only mild features.

Neuroimmunology: interactions between the immune and nervous systems

Group A streptococcal throat infections can cause an immunological reaction resulting in rheumatic fever in some children. This is now very rare in the UK but occurs in certain non-Western countries, such as Brazil. Rheumatic fever is also associated with neurological reactions causing the movement disorder Sydenham's chorea (St. Vitus's dance). Unlike TS, it is more common in girls. It has been suggested that in some cases, where a streptococcus infection has triggered an explosive onset of TS, the cause may be a similar neurological reaction.

The theory is that the streptococcal infection produces antibodies against the basal ganglia, which is a part of the brain responsible for controlling movement. Anti basal ganglia antibodies (ABGA) are present in Sydenham's chorea, in cases of TS apparently associated with throat infection and also in about a quarter of TS cases not associated with known infection.

There has been controversy over the significance of this finding and whether ABGA could actually cause TS-like symptoms or whether they occur independently.

Perinatal factors: birth difficulties

There is some suggestion that people with TS are more likely to have experienced birth difficulties or that their mothers had a complicated pregnancy. To date there has been no controlled study of sufficient numbers to demonstrate if there is any medical basis for this hypothesis.

Current concepts

In summary, TS is a genetic neurological condition, most probably with a complex set of controlling genes. The ultimate goal of TS research would be to identify important genes, define what effects they have on the developing brain and to match them up with the different types or symptoms of TS.

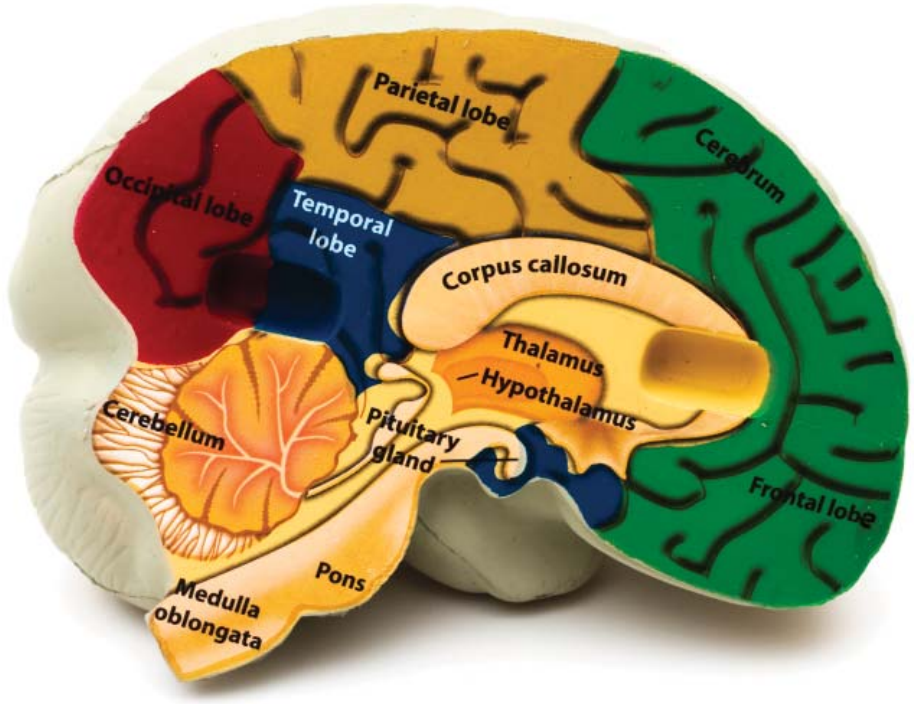
There are other potentially important factors, especially immunological, which could interact with genes in a complex manner.

What happens in the brains of people with TS?

Brain tissue (neuropathology)

Many neurological diseases are associated with brain tissue which is clearly abnormal, either to the naked eye or under the microscope. Conditions like TS, which are not degenerative or progressive, are less likely to be in this category, making it far more challenging to speculate on the nature of the dysfunction.

TS is a not a fatal disease, so far less autopsy material is available. To date, very few brains have ever been examined, although some patients have offered to donate their brains in the future. There are no major differences in the brains of people who had TS but some subtle findings have been reported. Most recently and interestingly, there has been a suggestion that during the development of the embryo, as cells are forming complex structures in the brain, certain neurons in the brains of people with TS may have migrated in an aberrant fashion.



Brain scans (neuroimaging)

Brain scans - CT (Computerised Tomography) and MRI (Magnetic Resonance Imaging) - of people with TS generally show normal results. However, MRI scans of groups of patients with TS do demonstrate subtle differences in the volumes of specific parts of the brain compared to control groups. These results have been somewhat inconsistent. However, they have implicated the basal ganglia amongst other brain regions.

Another approach is to measure the activity of different regions of the brain, or the relative activity of different neurochemicals, using MRI or radioactive labelled tracers. In patients with TS these studies have shown different kinds of activity in those parts of the brain controlling movement including, unsurprisingly, the basal ganglia.

Many studies have tried to demonstrate differences in the function of the chemical dopamine in people with TS. (See below.)

Recent research has focused on how tics may improve in patients as they grow older. Current thinking, based on evidence from brain scans, is that the frontal lobes may be important in suppressing tics. The hypothesis is that during childhood the frontal lobes of some people with TS become overactive in order to suppress their tics. Those adults with severe TS have not developed this capability - their frontal lobes have not become overactive. This hypothesis would explain some of the inconsistent results in earlier studies of the brain because it suggests that different structural and functional abnormalities may occur naturally in TS patients of different age groups.

Dopamine & other neurotransmitters

Dopamine is a chemical, related to adrenaline, which is secreted by the brain cells (neurons) to communicate with other neurons. Dopamine affects the basal ganglia system, which plays a major role in controlling movement. It is also involved in the limbic (emotional) part of the brain. Dopamine is the neurochemical that is deficient in Parkinson's disease (PD).

It is thought that TS may involve a dysfunction of the dopamine system. There are two reasons for this: firstly, the most effective drugs for tics are dopamine-blocking drugs; secondly, because TS is a movement disorder, the basal ganglia are implicated. This is sometimes known as the 'dopamine hypothesis'. It has been hard to assemble convincing evidence that the dopamine system plays a major role in causing symptoms rather than merely suppressing them. There has been little neuropathological (post-mortem) data to prove this. Some brain scanning studies have supported this hypothesis, whilst others have not. It is certainly possible that dopamine is important, despite negative studies in some cases. It is also eminently possible that other neurotransmitters, such as serotonin and opioids, are involved or are even more important.

Treatment

Research into medical treatment of TS is exceedingly difficult for three main reasons. Firstly, the severity of symptoms is very hard to measure objectively. Rating scales exist but they all have limitations. Secondly, the severity of TS fluctuates naturally without treatment. Thirdly, individuals have hugely varied responses to medicines.

Non-drug treatment

Drug treatment is not the only option. Psychological cognitive-behavioural approaches also have evidence to support them. This is standard treatment for OCD, best established in adults, that can also be applied to tics using a package of measures known as Habit Reversal Training. Although there is only very patchy experience in the UK, it has been relatively well explored in clinical trials and its effectiveness has been demonstrated.

There is little evidence for other non-drug treatments. Patients and parents are often interested in the influence of diet, for which we have little reliable data so far.

Drug treatment

There are numerous reports of a multitude of different drugs being used successfully in a small number of TS patients. In other areas of medicine, this evidence would not be considered strong enough to judge the effectiveness of a treatment. Trials using small numbers of patients are especially likely to yield spuriously positive results in TS. They should be considered as pilots only. There are far fewer larger double-blind placebo-controlled trials.

Currently, drugs are prescribed to relieve symptoms; to treat tics, for ADHD and for OCD. There are standard medical treatments for ADHD and OCD which are also used in TS. Often, ADHD and OCD are more important targets for treatment than the tics. Treatments for ADHD can theoretically make tics worse and were traditionally not recommended in TS but recent trials suggest this view may be incorrect.

The standard treatment for tics is neuroleptics, dopamine receptor blocking drugs. Their main use is for psychosis but there is no clinical link between TS and psychosis. Individual patients respond to different drugs in a variety of ways that is dramatic and unexplained. People with TS with a range of severities can find that their tics are well controlled by drugs; or alternatively that drugs have little to offer them. Adverse effects also vary from person to person.

There is a major need to improve the effectiveness and reliability of our pharmaceutical control of the symptoms.

Neurosurgery

Neurosurgical treatments for Parkinson's disease (PD) and some other movement disorders are now well established. From the 1990s, small areas of the basal ganglia were lesioned (cut) using a technique called stereotactic surgery.

A recent development in treatment for PD is deep brain stimulation (DBS). DBS involves implants which deliver high frequency electrical pulses to specific areas of the brain.

The model can be criticised in a number of ways. The theory that the treatment works by suppressing the area of brain to which it is applied may be simplistic. However, clinical trials show conclusively that these approaches can work in reducing the symptoms of PD.

TS is very different. We do not have a compelling model of what parts of the brain may be causing the symptoms because, unlike PD, there are no discernible changes in brain structure. However, like PD, TS is also a disorder of movement in which the basal ganglia are implicated. There has been great interest in evaluating the effect of DBS to this part of the brain.

Internationally, fewer than 50 DBS operations have been performed to date, the vast majority in adults. The largest study published so far consists of 18 individuals. Guidelines for how patients should be selected have also been published.

So the experience to date is encouraging but still experimental. No operations done in the UK have been documented to date. DBS could in future become an important treatment for people with severe TS but this will only be established with further well-documented experience.

Glossary and further information

Antihypertensive - A medicine prescribed to reduce blood pressure. Antihypertensive agents, clonidine (Catapres) and guanfacine (Tenex), are also used to treat tics; studies show variable efficacy, but a fewer likely side effects than the neuroleptics.

Anxiety - Can show as sleep difficulties, tension habits, motor unrest, phobias, worries, poor concentration, or panic attacks.

ADHD Attention Deficit Hyperactivity Disorder - Condition characterised by an impaired ability to regulate activity level (hyperactivity), attend to tasks (inattention), and inhibit behaviour (impulsivity). For a diagnosis of ADHD, the behaviours must appear before an individual reaches age seven, continue for at least six months, be more frequent than in other children of the same age, and cause impairment in at least two areas of life (school, home, work, or social function). Adults too may show signs of ADHD such as overly impulsive behaviour and concentration difficulties.

Basal Ganglia - Several large clusters of nerve cells, including the striatum and the substantia nigra, deep in the brain below the cerebral hemispheres; responsible for motor movements.

CBT Cognitive Behavioural Therapy – Psychological treatment for mental health conditions. Treatment usually takes between eight and 20 sessions. A combination of cognitive and behavioural therapies. CBT is based on the assumption that most unwanted thinking patterns and emotional and behavioural reactions are learned over a long period of time. The aim is to identify the thinking causing the unwanted feelings and behaviours and to learn to replace this thinking with more positive thoughts. The therapist does not focus on past events (such as childhood) but on current difficulties. The goal is to teach new skills and ways of reacting.

Comorbidity - Presence of more than one disease or health condition in an individual at a given time. OCD and ADHD are often comorbid with TS.

Conduct disorder - Can show as persistent and repetitive lying, stealing, truancy, starting fires, vandalism, fighting, or cruelty to animals.

Copropraxia and coprolalia - Copropraxia: making obscene or otherwise unacceptable movements or gestures. Coprolalia: using obscene or unacceptable language. This may involve swearing or racist remarks. Coprolalia can cause serious problems at school, in society and at work, and it is particularly sad that the words uttered usually bear no relation to the true feelings of the person saying them.

DBS Deep Brain Stimulation - Electrodes are implanted in the brain and stimulated by a surgically implanted pulse generator in the upper chest. Several studies have shown that this surgical intervention may aid in the amelioration of involuntary movements in patients with Parkinson's Disease and Essential Tremor. More recent studies have shown promise for other disorders including Dystonia (a movement disorder which causes involuntary contractions of the muscles, resulting in twisting and repetitive movements

and can be very painful). Early experience with DBS for tics in TS has been mixed. While some individuals have experienced a reduction in symptoms, others have not. There is no long-term follow-up yet to indicate whether symptoms will return. There might be serious risks involved, including cerebral bleeding and infection.

DA Dopamine agonist - Drug that acts like dopamine. These drugs bind to dopamine receptors in place of dopamine and directly stimulate those receptors.

Depression - In TS depression is most commonly seen in people with severe tics, sleep disturbances or OCD. Clinical depression is a common psychiatric disorder, characterised by a persistent lowering of mood, loss of interest in usual activities and diminished ability to experience pleasure. Depression should always be taken seriously. It is treatable and medical advice should be sought.

Dopamine - A neurotransmitter (naturally produced chemicals by which nerve cells communicate) that controls movement and balance. Essential to the proper functioning of the central nervous system (CNS). Dopamine assists in the effective transmission of electrochemical signals from one nerve cell (neuron) to another.

Dopamine antagonist - Binds to and blocks the action of dopamine receptors, essentially hindering receptor activity by preventing stimulation by dopamine. Antagonists can prevent or reverse the actions of dopamine by keeping dopamine from attaching to receptors.

Double-blind placebo-controlled (trial) - The gold standard for clinical trials. The placebo (inactive substance) is given to one group of participants, while the treatment being tested is given to another group. Neither patients nor those administering know which group receives the placebo, so their expectations cannot influence the outcome.

Echophenomena – Echolalia: repeating other people's words. Echopraxia: repeating other people's gestures. Common in TS.

Epidemiology - The study of diseases or conditions in human populations and the factors that influence their incidence and prevalence.

Epigenetics – The study of the heritability of characteristics without a change in DNA but due to other effects, such as environment.

Epiphenomenal - A secondary phenomenon that occurs alongside a primary phenomenon. This can be as a consequence of the primary phenomenon (for example a side effect could be epiphenominal of medication) or occurring independently.

Full Blown – Although this term implies that the disease or disorder cannot be developed any further, it is used to describe the middle level of severity of TS. This can be misleading, as the severity of TS can increase to become 'Tourette's Plus'.

Genetics - Field of science that looks at how traits are passed down from one generation to another, through the genes.

Health Psychology - The specific field in psychology concerned with psychology's impact on health, physical well being, and illness.

Inappropriate sexual behaviour - Usually involves touching the person's own or other people's genitals.

Limbic – Related to the part of the brain involved in emotion, motivation, and emotional association with memory.

Neuroleptic drug – An antipsychotic drug that may produce a state of apathy, lack of initiative and limited range of emotion. In psychotic patients, neuroleptic drugs cause a reduction in confusion and agitation and tend to normalise psychomotor activity.

Neuroanatomy - Anatomy of the brain, spinal cord and peripheral nervous system.

Neuroimmunology - Branch of biomedical science that studies all aspects of the interactions between the immune system and nervous system.

Neurology - Diagnosis and treatment of diseases and disorders of the nervous system.

Neuropathological – Related to nervous system tissue

Neurosurgery - Surgical treatment of diseases and disorders of the brain and nervous system.

Neurotransmitters - Chemicals that are used to relay, amplify and modulate signals between a neuron and another cell.

NOSI - Non-Obscene Socially Inappropriate behaviour - Falls short of swearing, but involves saying or doing things that are socially unacceptable; for example, personal remarks about height, weight or facial features.

OCD Obsessive Compulsive Disorder – Anxiety disorder characterised by repeated intrusive thoughts and associated ritualised behaviours intended to alleviate that anxiety. Compulsions typically include checking, ordering, counting, repeating, getting things 'just right' or symmetrical, or forced touching which is a different spectrum from the symptoms of 'pure' OCD. Examples include touching an object with one hand after touching it with the other hand to 'even things up' or repeatedly flicking the light switch on and off. In more serious cases, the obsession may have sexual, violent, religious or aggressive themes.

OT Occupational Therapy - Treatment to restore a physically disabled person's ability to perform activities of daily living such as walking, eating, drinking, dressing, toileting and bathing.

Paliphenomena - Similar to echophenomena but involves the person with TS repeating their own words and actions eg "Hello, I came here by bus bus bus bus".

PANDAs Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections – Disorders affecting some children with OCD and/or tic disorders such as TS. Their symptoms worsen following strep infections such as strep throat or scarlet fever. The children can have dramatic onset of symptoms, including motor or vocal tics, obsessions, and/or compulsions. Children may also become moody, irritable or show concerns about separating from parents or loved ones.

Parkinson's Disease - A chronic and progressive neurological disorder affecting control over movement, balance, coordination and speech.

PDD Pervasive Developmental Disorders – Neurological disorders usually evident by age three. In general, children who have a type of PDD have difficulty in talking, playing with other children and relating to others, including their family. According to the definition set forth in the DSM-IV, PDDs are characterised by severe and pervasive impairment in several areas of development: social interaction skills, communication skills, or the presence of stereotyped behaviour, interests, and activities. PDD refers to a group of five disorders: (1) Autism, (2) Rett syndrome, (3) Childhood disintegrative disorder, (4) Asperger syndrome, and (5) Pervasive Developmental Disorder Not Otherwise Specified (or PDD-NOS).

Perinatal – During and immediately after childbirth.

Physiotherapy - Use of physical and mechanical means, such as massage, regulated exercise, water, light and heat, to treat disease.

Placebo - Inactive substance or treatment that looks the same as, and is given the same way as, an active drug or treatment being tested. The effects of the active drug or treatment are compared to the effects of the placebo.

Polygenic - Characteristic that is controlled by multiple genes.

Prevalence – Proportion of cases in the population; calculated by dividing the total number of cases in the population by the number of individuals in the population, eg one percent of schoolchildren are affected by TS.

Prognosis - Likely or expected development of a disease or of the chances of getting better.

Psychology - The scientific study of human and animal behaviour.

Psychopathology – Refers to either the study of mental illness or mental distress or the manifestation of behaviours and experiences which may be indicative of mental illness or psychological impairment. Examples of psychopathology sometimes found in people with TS include rage attacks/aggression, oppositional defiant disorder and inappropriate sexual behaviour.

Psychopharmacology - Study of the effects of drugs on mood, sensation, consciousness, or other psychological or behavioural functions.

Psychosis - A mental state often described as involving a 'loss of contact with reality'.

Pure Tourette Syndrome – A proposed sub-type of TS, defining TS with no comorbid features.

Rage attacks - Frightening and destructive violent outburst, often without provocation or disproportionate to the trigger. Once begun, a rage attack has to be left to run its course. Rage may be linked to tic suppression.

Ratings Scales - Designed to assess the severity of tics. There are a number, all with limitations. The most well known include The Yale Global Tic Severity Scale (YGTSS; Leckman et al., 1989) and the Motor tic, Obsessions and compulsions, Vocal tic, Evaluation Survey (MOVES; Gaffney, Sieg, & Hellings, 1994). There are many others.

RCT Randomised Control Trial – One of the most commonly reported methods for evaluating the effectiveness of treatments. People are allocated at random to receive one of several clinical interventions. One of these interventions acts as a comparison to provide a benchmark. Randomised controlled trials are the most rigorous way of determining whether a cause-effect relation exists between treatment and outcome and for assessing the cost effectiveness of a treatment.

Selective Serotonin Reuptake Inhibitors (SSRIs) - A drug that blocks the removal of serotonin from the synapse; thereby prolonging and increasing the effects of serotonin.

SIB - Self-injurious behaviour. It includes punching and slapping the head, face or body, or scratching or sticking sharp objects into the body, including the eyes. It can be an obsessional behaviour.

Sleep Disorders – A group of syndromes characterised by disturbance in the patient's amount of sleep, quality or timing of sleep, or behaviours or physiological conditions associated with sleep. Frequent awakenings, sleep talking or walking are fairly common among people with TS.

Stimulant Medication – Drugs that increase the release or block the reabsorption of dopamine and norepinephrine, two brain neurotransmitters. In adults, they have the effect of making people more alert, active and awake. In children, they can increase attention and reduce hyperactivity, and are used as one part of the treatment for hyperkinetic disorder and ADHD.

Tourette Syndrome Plus – Proposed sub-type of TS, which includes TS with ADHD, OCB or OCD, and/or Self-Injurious Behaviours. Includes TS patients with depression, anxiety, personality disorders, Oppositional Defiant Disorder, Conduct Disorder and any other learning problems.

Waxing and waning – Commonly used to describe the fluctuations in tic severity with TS. Tics can worsen (wax) and lessen (wane) with a frustrating lack of predictability.

Further reading

About Tourette Syndrome

- 'Tictionary: A Reference Guide to the World of Tourette Syndrome, AS, AD/HD and Obsessive Compulsive Disorder for Parents and Professionals' by Becky Ottinger.
- 'Tics and Tourette Syndrome: A Handbook for Parents and Professionals' by Isobel Heyman and Uttom Chowdhury.
- 'Tourette Syndrome - The Facts' (Second Edition) by Mary Robertson and Andrea Cavanna.

Books for Teachers and Parents

- 'Anger Management Games For Children' by Deborah M. Plummer
- 'Disorganized Children: A Guide for Parents and Professionals' by Samuel M. Stein and Uttom Chowdhury
- 'Teaching the Tiger: A Handbook for Individuals Involved in the Education of Students With Attention Deficit Disorders, Tourette Syndrome or Obsessive Compulsive Disorder' by Marilyn P. Dornbush PhD and Sheryl K. Pruitt
- 'The Good Schools Guide to Special Educational Needs 2008' by Sandra Hutchinson
- 'Tourette Syndrome: A Practical Guide for Teachers, Parents and Carers' by Amber Carroll and Mary Robertson
- 'Kids in the Syndrome Mix of ADHD, LD, Asperger's, Tourette's, Bipolar and More!: The One Stop Guide for Parents, Teachers and Other Professionals' by Martin L., M.D. Kutscher, Robert R. Wolff and Tony Attwood

Books for Children and Teenagers

- 'Breaking Free from OCD: A CBT Guide for Young People and Their Families' by Jo Derisley, Isobel Heyman, Sarah Robinson and Cynthia Turner
- 'Hi, I'm Adam: A Child's Book about Tourette Syndrome' by Adam Buehrens
- 'I Can't Stop: A story about Tourette Syndrome' by Holly L. Niner
- 'Quit it' by Marcia Byalick.
- 'Tic Talk: Living with Tourette Syndrome'by Dylan Peters.
- 'Touch and Go Joe: An Adolescent's Experience of OCD' by Joe Wells
- 'Why do you do that? A Book about Tourette Syndrome for Children and Young People' by Uttom Chowdhury and Mary Robertson.

For your notes

"Where does Tourette's end? Where does my personality start? These are questions that I can't answer. Tourette Syndrome is something that manifests itself in every part of my daily routine. It is something that is literally with me every breath that I take. " Paul

"I know that my Tourettes could have changed me into something I don't like, but for some reason it didn't – it did just the opposite." Francesca

"I've come to terms with it. It gives me a unique character, and I'm proud of that. " Ruth

**Some names in this publication have been changed to protect anonymity.*

Edited from a presentation given by Dr Jeremy Stern at the Tourettes Action Research Symposium 2008, with additional materials from members and supporters.

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Tourettes action

About Tourettes Action

www.tourettes-action.org.uk

Tourettes Action is the UK's leading support and research charity for people with Tourette Syndrome (TS) and their families.

Tourettes Action's vision is for people with TS to receive the practical support and social acceptance they need to help them live their lives to the full. Services are designed to offer support to people with TS throughout their lives and focus on delivering the appropriate information, practical help and opportunities for social contact at each stage: childhood, adolescence, and adulthood. Tourettes Action also works to educate and inform health and social care and other statutory agencies of the true nature of TS.

Some services are available only to members. Annual membership is £20.

Tourettes Action produces a range of publications. Many of these may be downloaded at no cost from our website.

Education Issues and Tourette Syndrome: an introduction for parents & schools is available from our website www.tourettes-action.org.uk or by telephoning 020 7793 2356.

Free Helpdesk

Call **0845 458 1252**
9am to 5pm, Monday to Friday.

Email **help@tourettes-action.org.uk**

Write **Helpdesk**
Tourettes Action
Southbank House
Black Prince Road
London SE1 7SJ

*understanding
the misunderstood

supporting people with TS through all the stages of their lives

facilitating inclusion in society by raising accurate awareness of TS

funding and facilitating research

For more information on Tourette Syndrome and our services, see our website at **www.tourettes-action.org.uk** or contact our Helpdesk by calling **0845 458 1252** or emailing **help@tourettes-action.org.uk.**

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