



Tourette Syndrome

Questions and answers



A briefing from the
Tourette Society Germany e.V.

Tourette-Syndrome

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2017

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QUESTION: WHAT IS TOURETTE SYNDROME?

Answer: Tourette syndrome (TS) is a neuropsychiatric disorder characterised by tics. The tics consist of mostly involuntary, rapid, and generally sudden movements, which can occur again and again in the same way, but are not rhythmic and can also occur during sleep.

The symptoms include:

1. multiple motor (muscle twitching) and one or more phonic (vocalisation) tics. The latter occur during the course of the disease, but do not necessarily occur simultaneously with the motor tics;
2. the occurrence of tics several times a day (usually in series), almost every day or repeatedly over a period of more than one year;
3. periodic changes in the frequency, type and localisation of the tics as well as an increase and decrease in their manifestation. The symptoms can sometimes disappear for weeks or months, but also reappear unexpectedly.
4. The disease almost always begins before the age of 18.

The term “involuntary”, which is used to describe the tics, sometimes leads to misunderstandings, since most people who are affected by TS have a premonitory urge before a tic and/or a certain self-control over their symptoms. In many cases, it is unfortunately not known that the self-control, which can be perceived by the patient for seconds to hours, usually only means a delay of heavy “tic discharges” and rather rarely stops the manifestation of the suppressed tic. Usually, the urge to complete the tics is so strong that finally the muscle twitching or the vocalisation must occur (comparable to the urge to sneeze or a hiccup). People with TS often seek a protected environment to free their symptoms after they have tried to not show them at work or at school. Typically, tics are associated with irritating or joyful excitement, tension or stress.

In a relaxed state or when concentrating on an interesting task, they tend to drop.



QUESTION: HOW ARE TICS CLASSIFIED?

Answer: There are generally four categories of tics, here are some examples:

Simple tics:

Motor	eye blinking, head jerking, shoulder jerking, grimacing
Phonic	throat-clearing, whimpering, squealing, grunting, sniffing, tongue clicking

Complex tics:

Motor	jumping, touching other people or things, smelling, body-twisting, sometimes self-injurious behaviour (e.g. hitting and pinching oneself, hitting one's head), echopraxia (imitation of another person's actions), copropraxia (performing obscene acts)
Phonic	utterance of words and short sentences which are not logically related to the topic of the conversation, coprolalia (utterance of inappropriate words), echolalia (repetition of sounds or word fragments which have just been heard); palilalia (repetition of self-spoken words).

The range of tics or tic-like symptoms that can be detected with TS is very wide. The complexity of some symptoms often evoke great astonishment, amazement, or annoyance in family members, friends, teachers, or co-workers. There is often the impression that it is hard to believe that these actions and utterances are indeed involuntary. Therefore, some people feel provoked by the tics.



QUESTION: DO ALL PERSONS WITH TOURETTE SYNDROME HAVE OTHER BEHAVIORAL PROBLEMS BESIDES THE TICS?

Answer: Not all, but a large proportion of people with TS have additional problems, and they do not necessarily have to originate from TS, such as:

Compulsive behaviour and ritualised behaviour

For example, the person concerned has the feeling that something has to be done over and over again until it is “right”, which can also apply to a tic movement. It may also include touching things that need to be touched, for example, with one hand to “make things equal” or “make it symmetrical”. It is also possible that the person concerned has to check repeatedly whether the stove is switched off, the door is properly closed etc. Children sometimes ask their parents to repeat a sentence several times until it “sounds right”.

Motor hyperactivity with or without attention deficit

This is found in many people with TS. In children, signs of hyperactivity can be seen before TS symptoms occur. Indicators for hyperkinetic syndrome¹ include: Difficulties with concentration; problems of bringing started things to an end; not able to listen; easily distracted; often acting before thinking; steady and rapid change from one activity to another even before it is finished; the children need a lot of supervision and regulatory aids from the outside. Adults may also have signs of a hyperkinetic syndrome, such as lack of cognitive or emotional impulse control and concentration difficulties.

¹ Currently, the term ADHD (attention deficit/hyperactivity disorder) is increasingly used



Learning difficulties

Such as having trouble reading, writing and doing arithmetic as well as problems of differentiated perception (e.g. figure-background distinction of a complex type).

Difficulties with the impulse control

As already mentioned, in very rare cases it may lead to very aggressive (words, actions) or socially inappropriate behaviour.

Sleep disorders and depression

Are certainly to be found in individuals with TS. This includes sadness, listlessness, withdrawn behaviour, difficulty falling asleep, frequent nocturnal awakening, or even sleepwalking or sleep-talking.

QUESTION: WHAT ARE THE INITIAL SYMPTOMS?

Answer: The most common is a facial tic, such as blinking, a sudden, fast eye squint, distortion of the corner of the mouth, or sudden mouth opening. It is also possible to see involuntary vocalisations such as throat clearing and sniffing, or muscular twitching in the region of the extremities (e.g. sudden symmetrical arm curls) as initial symptoms. Sometimes the disorder starts abruptly with several symptoms, that is, muscle twitching and vocalisations occur almost simultaneously.

QUESTION: WHAT CAUSES THE SYMPTOMS?

Answer: The cause has not yet been discovered, although current research suggests that a disrupted metabolism of at least one chemical substance in the brain exists in TS. It involves the chemical substance dopamine. This is a so-called neurotransmitter, a carrier substance in our brain, which is important for signal transmission (e.g. in the context of motor signals). However, it is assumed that other neurotransmitters, e.g. serotonin, are also affected.



QUESTION: IS THE TOURETTE SYNDROME INHERITABLE?

Answer: Genetic studies indicate that there is at least one inherited form of TS. It is very probable that this is a pattern of genes of varying importance, which (in conjunction with other factors) causes the diversity of the symptoms in the individual family members. A person with such a TS passes such genes to one of their children with a 50% probability at each pregnancy. However, this genetic predisposition (hereditary affliction) can show up later, if at all, as TS of different manifestations: e.g. as a mild motor tic disorder or as a tic disorder with compulsive characteristics. It is known that TS families often randomly have family members with mild tic disorders and compulsive behaviours. The gender of the child also affects how the gene pattern becomes effective. The likelihood that a child with TS genes will develop symptoms (whether mild or severe) is at least three to four times higher with a son compared to a daughter. However, only about 10% of children with TS genes develop TS symptoms severe enough as to require medicinal treatment. In addition to the inherited form of TS, there are also non-inherited forms, that is, the so-called sporadic forms of TS. The cause in these cases is usually completely unknown. Only in a few patients can an infection with, for example, streptococci be ruled as a cause.

QUESTION: HOW IS TOURETTE SYNDROME DIAGNOSED?

Answer: The diagnosis is made by the fact that the corresponding symptoms are observed and the course of the disease so far is precisely examined. There is no blood analysis or any other type of neurological or psychological examination that enables the diagnosis of TS. In some cases, an electroencephalogram, a cranial computer tomogram or a nuclear magnetic resonance tomogram or other medical examinations are useful to be able to reliably distinguish TS from other neuropsychiatric disorders. Questionnaires and rating scales are available to better assess the nature and severity of the tic disorder



QUESTION: IS THERE A THERAPY THAT LEADS TO COMPLETE CURE?

Answer: So far, unfortunately not.

QUESTION: CAN WE EXPECT A DECLINE IN THE SYMPTOMS?

Answer: A number of people experience a significant improvement as adolescents or young adults (between 15 and 25 years). Many people with TS get better in the course of their development from child to adult. People with TS have a normal life expectancy. In individual cases, a complete and permanent regression of the symptoms has also been reported.

QUESTION: HOW WOULD YOU DESCRIBE A TYPICAL CASE OF TOURETTE SYNDROME?

Answer: The word “typical” cannot be easily applied to TS. The symptoms are manifested in a wide range from very mild forms (and this applies to most affected people) to very severe forms that only a few persons have to endure.

QUESTION: HOW IS TOURETTE SYNDROME TREATED?

Answer: Most people who are presented with TS are not significantly affected by their tics or their behavioural difficulties, and therefore do not need any medication or other professional assistance. If, however, motor and phonic tics are to be treated, we have various medications available to control the symptoms if they pose a particular burden on the affected person and his/her family. In Germany, the active ingredient tiapride (Tiapridex®) is used for first-line therapy; but risperidone (Risperdal®), pimozide (Orap®) and haloperidol (Haldol®) can also be used.

In some cases in the USA, clonidine (Catapresan®), fluphenazine (Dapotum® or Lyogen®), Olanzapine® (Zyprexa®) and



clonazepam (Rivotril®) are still used, without a well-documented efficacy. Stimulants such as methylphenidate (Ritalin®, Medikinet®, Equasym®, Concerta®) or pemoline (Tradon®), which are prescribed in children with a hyperkinetic syndrome, can sometimes intensify tics. One should therefore be cautious about their use in children with tic disorders. If TS is accompanied by severe obsessive-compulsive disorder, medicating with, for example, clomipramine (Anafranil®), fluvoxamine (Fevarin®), sertraline (Zoloft®) or fluoxetine (Fluctin®) may be appropriate. The drug sulpiride (Dogmatil®) enables the treatment of two disorders in one substance with the combination of TS and obsessive-compulsive disorders. The dose required to achieve optimal control of the symptoms varies from patient to patient and must be properly coordinated with the patient and family to the individual needs of the patient. As a rule, the medication is administered at low doses with a gradual increase in the amount, to reach the point where the best effect with the least side effects is achieved. Some adverse reactions to the medication can include weight gain, fatigue, mild motor restlessness, or (as with haloperidol for example) painful muscle stiffness. Most of the symptoms can be avoided by reducing the dosage. Other side effects (e.g. muscle stiffness) can be improved by using special additional medication. Sometimes, side effects also include listlessness, depression, listlessness, tendency to withdraw, and reduction of mental activity. Here, too, a reduction in the dosage or a change in medication improve the difficulties.

Other types of treatment may also be helpful. For example, relaxation techniques, anti-stress training, biofeedback techniques and other behavioural therapies can help alleviate stress responses (which otherwise intensify tics); on the other hand, they can also improve the self-control of tic symptoms. For example, the “reaction reversal-motor response” programme can be used to “counteract” an unpleasant tic by means of voluntary movement, or replace the tic with a movement that is more socially acceptable.

Other psychotherapeutic measures can also be used to support a concerned person and his/her family so that the internal and external treatment of TS can be better achieved.



QUESTION: HOW MANY PEOPLE WITH TOURETTE SYNDROME ARE THERE IN GERMANY?

Answer: The daily experience shows that there are many people with TS who have not yet been diagnosed. Therefore, the available figures may represent only approximate values. It is around 0.05-3% worldwide. If these figures are transferred to Germany, at least 40,000 people would have to live with TS.

QUESTION: DO PATIENTS WITH TOURETTE SYNDROME NEED SPECIAL EDUCATIONAL, SCHOOL OR PROFESSIONAL HELP?

Answer: Children with TS have about the same mental performance as other children of their age. Still, many children with TS have learning difficulties. This is mainly due to the fact that approximately 50% of the children with TS are also affected by a hyperkinetic syndrome. They also have their tics to cope with (disturbances in writing, being teased). A suitable solution must be found for each individual child. This can range from the use of typewriters or computers due to reading or writing problems, examinations in special rooms when phonic tics are a major problem, having permission to leave the classroom when the tics are insurmountable. If other behavioural problems develop, measures can be implemented which are also offered in children without TS, for example, as part of the children and adolescent psychiatry.

Everyone – with and without TS – should choose a profession according to their inclinations and abilities. Members the Tourette Society Germany e. V. affected by TS include individuals in various professions such as musicians, engineers, doctors, workers, farmers, educators, butchers and policemen.

For tics that are clearly visible and audible, a profession with a lot of customer traffic can be problematic. People who are seriously affected by TS must come to terms with restrictions on their personal and professional life. They can and should use all available aid provided by the state.



QUESTION: IS IT IMPORTANT TO TREAT TOURETTE SYNDROME EARLY?

Answer: Yes, especially in those cases, where the symptoms are so pronounced that the children are presented as bizarre, disturbing and fear provoking, and the child and the environment suffer from TS. It is not uncommon for TS that the children are laughed at, rejected by their peers; neighbours, teachers and other people complain about the children, criticising the parents. Even the parents themselves can be frightened by the strange behaviours of their children. Moreover, with the first-hand experience of tic symptoms, the child can increasingly fall out of mental balance. These difficulties may develop further during the course of development, especially when adolescents are already in a difficult phase of development. In order to avoid such psychological consequences and to enable the child to develop as favourably as possible, an early diagnosis and an early treatment of the child and preparing the family are absolutely recommended.

QUESTION: WHAT KIND OF FAMILY SUPPORT IS AVAILABLE?

Answer: First and foremost, professional advice should be sought from children's and adolescent psychiatrists, paediatricians and neurologists. Since 1993, there is also a Tourette Society in Germany.

In this society, the affected persons, professionals and interested parties join together to achieve the following goals:

- fast information on new research results around the world,
- effective public relations work to reduce prejudices,
- advice and help with problems,
- experience exchange,
- promotion of therapeutic possibilities,
- stimulating research on TS.



QUESTION: WHAT KIND OF FAMILY SUPPORT IS AVAILABLE?

Answer: Parents who have a child with TS balance on a tightrope between educational necessity, understanding and over-protection. They are continually confronted with the question of whether certain actions of their child are an expression of TS or represent behavioural problems which could and should be corrected. Parents must then find the right form of treatment for their child. Parents of a child with TS should give their child the opportunity to develop as independently as possible. In doing so, they should not shy away from setting limits in a loving but consistent way, as would typically be the case with unaffected siblings.

QUESTION: WHAT IS A TOURETTE SOCIETY?

Answer: There are now Tourette societies in many countries. A particularly large organisation exists in the USA.

Just like this one, the Tourette Society Germany, founded as a non-profit organisation in 1993, intends to develop the following activities (see also above):

- Organisation of scientific conferences and information events for laymen and professionals
- Development and distribution of information material to individuals, professionals and organisations in the field of health care, education and administration
- Support for research activities to eventually find the cause and treatment for TS and at the same time to help improve treatment options (e.g. through medicine)
- Supporting affected persons in all aspects of their problems

QUESTION: WHY SHOULD YOU BECOME A MEMBER OF THE TOURETTE-SOCIETY?

Answer:

- It is also possible to discuss common problems with other patients and families within the framework of the organi-

sed meetings and to find helpful support for themselves and others.

- To help identify and treat TS at an early stage.
- To receive the best and up-to-date information on TS through the newsletters of the Tourette Society Germany, be it diagnostics, treatment, research programs or scientific developments.
- To help coping with TS.

QUESTION: WHERE DID TOURETTE SYNDROME GET ITS NAME?

Answer: In 1825, the first case of TS in the medical literature was described by the Frenchman Itard. It was about a noble lady, the Marquise of Dampierre. Her symptoms included involuntary motor tics of various types, as well as various vocalisations, including coprolalia and echolalia. She was 86 years old, and her case, together with a few other cases, were described in detail by the French neurologist Dr. George Gilles de la Tourette in 1885, after which the disease was finally named. Well-known writers, musicians, surgeons and sportsmen have been known to have TS.

QUESTION: WHY THIS BRIEFING?

Answer: This is intended to give every citizen the opportunity to gain information about TS. The questions and answers are not intended to replace medical or other professional advice. No one should start, change or stop treatment on the basis of this publication. It is highly advisable to consult a doctor first regarding such considerations.



QUESTION: WHERE CAN I FIND MORE INFORMATION?

Answer: Today, there is a range of information in the most diverse forms. An overview can be found on the website of the Tourette Society Germany e. V. at www.tourette-gesellschaft.de. You are also welcome to inquire about book recommendations by email at info@tourette-gesellschaft.de.

QUESTION: WHERE CAN I FIND MORE INFORMATION?

Answer:

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Comment:

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