

TOURETTE SYNDROME – THE SIMPLE TRUTH

A guide to TS for children and young people



Most people with Tourette Syndrome are diagnosed as children or teenagers. Children generally start to tic between ages five and seven, but they can start as young as three years old.

There is a lot of information about TS out there, but because it is a complicated condition a lot of the material can be quite difficult to read and understand. So Tourettes Action asked young people what questions they had about TS, and we've attempted to answer them here.

If you have any other questions remember that you can contact us at help@tourettes-action.org.uk.

About TS

What is TS?

Tourette Syndrome is when somebody makes movements and noises that they can't control. These noises and movements are called tics. Tics are usually fast and happen again and again.

Some tics might look like the person is making them on purpose, like when they pull a funny face, but they are involuntary movements and the person will continue making them when they are on their own. Tics are 'unnecessary' actions, for example a sniff tic can happen even when somebody doesn't need to blow their nose.

It's hard to describe what it feels like to have a tic, but try not to blink for as long as you can. The longer your eyes are open the more desperately you want to blink and that is what it feels like to tic.

Three times more boys than girls have TS. The first tics are often blinking, head and neck twitching or throat clearing.

Is TS just tics?

About 85 per cent of people with TS will also have associated conditions, like anger or behavioural problems and sleeping difficulties. There is a condition called Obsessive Compulsive Disorder where people experience repetitive and upsetting thoughts and/or behaviours,

and also attention deficit hyperactivity disorder (ADHD) where people might have difficulties with inattention, hyperactivity or impulsiveness.

Why is it called Tourette Syndrome?

About 165 years ago there was a doctor in Paris, France called Georges Albert Edouard Brutus Gilles de la Tourette. He was doing research into patients with tics and other symptoms and was the first person to suggest that they were all connected to the same condition. The condition is named after him, but it is also known as TS and Tourettes.

Can people catch TS?

No, people can't catch TS. TS is a neurological condition, which means that it is the way that your brain is structured that causes TS. You may only have developed symptoms recently, but you were born with the gene that causes TS. TS isn't like a cold or the flu, you can't pass it on to your family or friends.

Will I swear?

Only 10 per cent of people who have TS swear. Ticking using bad language is known as coprolalia and most people with TS don't have this tic. It is also uncommon for them to have other tics like copropraxia which is the making of rude/unacceptable movements or gestures.

Some of my tics are strange, am I weird?

The most common tics are things like eye blinking and throat clearing, but some tics can be much bigger and are known as 'complex' tics. These can be quite confusing for the person who has TS and people watching them, but they are still involuntary tics.

Some examples include: standing up and spinning around on the spot; touching a hot oven; kissing somebody or even kissing yourself; shouting out unusual sentences that make no sense to you or anybody else. If you have tics like these you aren't weird, it's just part of your TS.

Why do I tic sometimes, but not in certain places?

Tics can be made worse if you are stressed, nervous, excited or anxious, so you might find in some situations that you tic more than usual. For example, if you stand up in front of people to give a talk.

At the same time, there might be some places you don't feel comfortable to tic and then you might be able to suppress. For example, some people can suppress when they go to school but then have a big explosion, known as a tic attack, when they get home.

Should I suppress my tics rather than letting them out?

If you can let your tics out that is best because suppressing a tic doesn't make it go away, instead it stores it up for later. It's a bit like trying to hold in a sneeze. You might be able to hold it in but the longer you do the greater the urge to sneeze gets and then it usually comes out stronger than it would have in the beginning.

How can I make it stop? Will it go away?

Most people are diagnosed as children or teenagers, the earliest people are diagnosed is normally about seven years old. There is no cure for TS, but half of young people diagnosed will see their symptoms reduce to the point where they seem to disappear or become easily manageable by the time they are 18. For the other 50 per cent of young people who do not outgrow it, they will continue to live with TS as adults.

What happens when I go and see a doctor? And how often do I have to go?

When you go and see a doctor they will ask you about your tics, how often you do them and what kind of things you do. The first doctor you will see will be your GP who is the family doctor who your parents take you to if you are feeling ill. After they have spoken to you and your parents they will then contact a doctor who is a specialist, somebody who knows a lot about TS, and arrange an appointment for you to see them.



We know that seeing a doctor can sometimes be scary and you might be afraid to let your tics out, but remember that they are there to help you and the more information they have the better chance they have to help you, so try to tell them as much about your tics as you can.

When you see the specialist he will ask you lots of similar questions. To find out if you have TS he will carry out what is called a clinical diagnosis; this means that the doctor will talk to you and base his decision on meeting you. There are no medical tests like blood tests or scans to work out if you have TS.

The doctor should be friendly and kind and will want to talk to you as well as your parents. They will tell you how often you need to go back to see them which will depend on what level of TS you have, but you probably won't need to see them very often.

Do I have to take drugs to treat my TS?

Medication is one way that doctors treat TS and your doctor will discuss with you and your parents if you need to take any prescribed drugs. There are other treatments available for the symptoms of TS, including Habit Reversal Therapy, where you work with a doctor to train your body to react differently to the signals it is sending out, which can be helpful if you have tics that can potentially cause you or other people harm, or be socially unacceptable. For example, if your brain sends a signal to your hand to punch your leg, you can teach your body to recognise that signal and instead of punching your leg, you just make a fist with your hand. You should talk to your doctor about all the options available for treating TS.

What might help my tics?

As well as treatment from your doctor, you might find that other things can help reduce your tics. Relaxing, exercise, eating a healthy diet and keeping fit will help. Some people find playing sport reduces their tics, whilst others don't tic when they sing or play a musical instrument like the drums. For some people watching television or computer games helps them relax and reduces their tics. There are lots of activities out there that might work for you.

We know that some people might feel ashamed or embarrassed about their TS and try to hide it, which can cause even more stress and worsen your symptoms. Accepting your TS gives you freedom to be yourself and to build your self-confidence and ability to help people understand your condition.

Why do I get angry?

Anger and behaviour issues are connected to TS. If you feel yourself getting angry and you don't understand why you should tell your parents or your teacher. They can work with you to help you stop feeling this way and teach you ways to control the 'volcano' feeling that might be building up inside of you.

Am I disabled?

The term 'disabled' can be confusing. What you should remember is that having TS needn't stop you doing anything you want to do. Under UK law TS is considered a disability. This is a good thing as it means that you can get support if you need it in school or later on at work. But some people might have such mild TS that it does not impact enough on their lives to be considered a disability.



TS in school

Can I tic in school?

If you need to tic in the classroom or the playground you can. Talk to your teachers about your tics to limit how much they distract you and your friends in lessons.

For example, if you have a tic where you swing your arm out, you can ask to sit at a different desk where you are less likely to hit somebody. If you have loud vocal tics, you could agree a quiet space in the classroom where you let out your tics and then come back when you feel more relaxed. If you have difficulty taking notes in class talk to your teacher about ways they can help you.

Don't sit in silence, suppressing your tics. Talk to your parents and teachers, they want to help you achieve the best in school. Together you can work out how to prevent your TS impacting on your studies.

Do I need extra support in school or at exam time?

Not all, but some people with TS need extra support in school and at exam time because of their tics and other associated conditions. This might include having extra time to take an exam, or being allowed to have a stress ball to squeeze in class to help you relax. If you are finding it difficult to concentrate on your work, you should speak to your parents and teachers.

Will I get bullied if I tell people in school that I have TS?

Sadly, people can be bullied for lots of reasons. Not everybody with TS gets bullied, but sometimes they might get picked on because their tics make them stand out. The first thing to do if people call you names is to ignore it. Bullies usually want to provoke a reaction, so the best way to stop them teasing you is not to react to their comments.

If the bullying carries on though, it is important to tell somebody about it. You can tell your mum, dad, carer, brothers or sisters, teachers or friends. You can also write down about what is happening, or if you feel that you have nobody to talk to then you can call an organisation that helps children called Childline on 0800 1111. The most important thing is that you tell somebody about it.

Should I tell people in school that I have TS?

It is your decision if you want to tell people at school about your TS, talk to your parents and teachers to help you decide. We know that it can be scary to tell your friends, but you will probably find they are glad to know and that they won't think any differently about you, because you made the same noises and gestures before. Now they just know that it is because you have a condition called Tourette Syndrome.

How can I tell people in school that I have TS?

If you decide to tell people at school that you have TS there are lots of different ways to do it. Lots of people start off by telling their closest friends, either one by one or in a small group. You can answer any questions they might have and you will probably find they are really supportive.

You can ask your teacher to tell the rest of the class for you, if you like. They can use presentations that we have made for them, which they can read out to the pupils. If you want to be there when they read this out you can be, but if you would prefer not to be then that is OK too. Your mum and dad can come in as well to support you and help answer any questions.

Do I have to do homework?

Unfortunately, having TS is not an excuse to get out of homework! We know, though, that ticcing all day at school, or supressing your tics, can be exhausting and that the last thing you want to do when you get home is more work. So it is important to discuss with your parents and teachers the best way to do the homework that you have been set.

Break your work into small chunks that are easier for you to finish and try to keep a homework diary so that you can follow the work that needs doing. You might be able to do some of your homework in school at lunchtime. Talk to your teachers to see if this is an option for you.

Will I be able to go to university?

There is no reason why having TS should stop you going to college or university, lots of people with TS do and they have the same experiences and get just as good grades as everybody else. There might be things you need to think about though. For example, if your tics stop you

taking notes in lectures you might want to agree with your tutor that they will send you copies after the lesson. You can read more about support when at university in our 'TS at university' factsheet which is on the TA website.

TS at home

Why do I have it, but not my sister?

We don't yet know what causes TS, but we do know that there is a genetic link, which means that there is likely to be somebody in your family who also has TS. There symptoms might be very mild though, so you may not realise they have the condition too.

People with TS have a 50 per cent chance of passing the gene to their children. So it is very possible for you to have TS but for your sister not to, as she did not receive the TS gene.

Do my family hate me for having TS?

TS is hard for the person who has the condition, but it can also be difficult for families living with somebody with TS. Some of the symptoms can be tiring to live with as you know yourself, but they still love you.

Talk to your family about your TS and how they feel about it. You will probably find that they feel as frustrated as you about the condition, because they aren't able to stop your tics and make you feel better. Discuss ways to help your tics at home to reduce the impact for all of you.

How can I manage my tics at home?

There are some tics that can have an impact at home, either by putting you or your family in harm's way, or by affecting quality time you spend together. You can work around tics to limit the impact. How you do this depends on the specific tic, but below are some examples:

Avoiding danger at the dinner table

Tom has an arm tic, where he swings his right arm out violently without warning. At dinner time when he is holding a fork this can be dangerous for his brother who sits next to him and has to duck out of the way to avoid getting a fork in the eye. So Tom and his brother decided to swap places at the dinner table so that Tom's arm doesn't swing towards anybody anymore.

Staying safe in the car

When Emma's dad drives her to school in the car she usually sits in the front seat, but she has developed a tic where she jumps over and tries to grab the steering wheel. Because this is unsafe, Emma and her dad decided that it was best if she sits in the back. They also decided to put the child locks on the back doors so that she doesn't try to open them when they are driving along.



TS and my friends

Can I do the same things as my friends, like going to the cinema?

Having TS shouldn't stop you from doing anything any of your friends can do, like hanging out in the park, going to the cinema or eating in a restaurant.

It's fine to tic when you are out with friends and family, but you will know if there are some situations that aggravate your tics and you can plan in advance to avoid that. For example, it's probably best not to go and see a scary movie if you know being scared makes your tics worse.

If you are ticcing when you are out, somebody might ask you about your tics or tell you to stop because they don't realise you have TS. We make identity cards which you can show to people if you are asked about your tics. It explains to them that you have TS and helps them understand your noises and movements.

What will my friends say if I tell them I have TS? Should I tell them?

If you tic in front of your friends they will probably have noticed that you make unusual sounds or movements, even if you haven't discussed it with them. When most people with TS explain to their friends that they have the condition, it is really only giving a name to the thing that you already do.

Telling your friends is an opportunity to explain the condition to them and to answer any questions they might have. Good friends will help support you with your TS.

Will anybody want to go out with me?

Lots of people with TS have successful relationships, get married and have families of their own. If you meet somebody new who you like, explain TS to them so they know about the condition – it could be a great way to get the conversation going!

TS in everyday life

Will I be able to get a job?

Lots of people with TS work. There are people with TS who are doctors, lawyers, teachers, electricians and office workers. Having TS should not stop you pursuing your dreams about what you want to do.

Will I be able to drive?

Having TS doesn't mean you can't drive, lots of people do. A small number of people who have very severe TS might be unable to drive because of specific tics, but this is uncommon.

Can I use a phone?

People with TS can talk on the phone and some people find that when they speak on the phone their tics actually reduce. If you tic when you speak on the phone and are talking to somebody you have never spoken to before, it is a good idea to explain at the start of the conversation that you have TS.

Is there anybody famous with TS?

There are several famous people with TS around the world. Perhaps the most well-known is the Everton Football Club goalkeeper, Tim Howard, who also used to play for Manchester United. The 2006 winner of the TV programme Big Brother, Pete Bennett, has TS. Pete used his appearance on the show to raise awareness of the condition, including writing a book called 'My journey with Tourettes'.

In the US, Jim Eisenreich, a former Major League Baseball player for the LA Dodgers has TS. Some people also think that it is likely the composer Wolfgang Amadeus Mozart had TS.

What should I do when people laugh at me when I tic?

Sometimes tics can be funny and make you and your friends laugh, but when people make fun of you because you have TS it can make you feel sad. Most of the time, it is because people don't really understand what TS is. Explaining to people can often help, but if you don't feel able to do this try to ignore their comments. If the teasing gets really bad tell somebody about it, like a parent or teacher.

What should I do when people tell me off?

If people tell you off when you tic, explain to them that it is because you have TS and that you can't help it. You can also show them your identity card that you can get from TA, which explains the condition to them.

Will I upset people with my tics?

Most people who know you well will be able to tell the difference between a tic and your normal behaviour, so they won't get offended. However, some tics can upset and offend people who don't know that you have TS, for example, if you have coprolalia, where you tic swear words.

The best thing to do if you think you might have said or done something that could upset somebody is apologise and explain that you have TS. You can show them your TA identity card too.

Will I get arrested if I do something because of my TS?

Having TS does not make it more likely for you to be arrested. If you are ever stopped by the police who question your behaviour explain to them that you have TS and show them your TA identity card. Remember, however, having TS is never an excuse for committing a criminal offence.

I find it hard to sleep because of my TS and don't know what to do.

Having problems sleeping is a common issue for many people with TS. There are some strategies that could help including relaxing before bed by reading a book or listening to some calming music. Get a black out blind for your bedroom so that you don't get woken up by light outside. Weighted blankets have proved successful for some people, but they are quite expensive. You can see if it might work for you by putting extra blankets or duvets on your bed to make the covers heavier.

Support for people with TS

Am I the only person with TS?

Not everybody gets diagnosed so we don't know exactly how many people have TS, but there are about 300,000 people in the UK with the condition and many more around the world.

Can I meet other people my age who have TS?

There are lots of ways to meet other people your age with TS. The best is to come along to one of our TA support group meetings. We have groups around the country so there should be one near you. They are open to people with TS and their families, so you don't have to go alone. Talk to your parents about going along to the next group. You can find a list of groups on our website.

Who can I talk to about TS?

If you have any questions about TS don't hold them in, it is much better to talk to somebody. You can speak to



your mum, dad, brother, sisters and teachers. If you have specific questions about TS contact our Helpdesk, or you can sign up to our online forum to speak to share your experiences. Support groups are a great way to meet other people with TS, so ask your parents about going along. If you feel that you have nobody to talk to then you can call an organisation that helps children called Childline on 0800 1111.

Find out more

Information from Tourettes Action

- **TA website** – we have lots more information about TS and support available
- **Facebook** – like Tourettes Action to find out all the latest news about TS and upcoming events
- **Twitter** – follow us for the latest news on TS
- **TA forum** – share your experiences with other people your age with TS
- **Youtube** – visit our Youtube page to watch videos from fellow ticcors talking about what it is like to have TS

Information online

- **Tourette Syndrome Canada** – has a good collection of videos about TS
- **Tourettes Hero** – a blog from Jess Thom about living with TS

Books

- **Why do you do that? A book about Tourette Syndrome for children and young people** – Uttom Chowdhury & Mary Robertson
- **A family's guide to Tourette Syndrome** – (eds) Walkup, Mink & McNaught