

Patient information from BMJ

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Tourette's syndrome

If you, your child, or someone close to you has Tourette's syndrome it can be distressing and confusing for everyone involved. But learning about the condition and getting treatment can help.

You can use our information to talk to your doctor about the best treatment for your child.

What is Tourette's syndrome?

When someone has Tourette's syndrome they have what are called tics. Tics are repeated movements or sounds that they can't help making. For example, they might squint or make squeaking noises.

Not every child with tics has Tourette's syndrome. Plenty of children have mild tics and repetitive habits that come and go and don't cause them any problems. Tourette's is more severe and longer term.

The tics with Tourette's follow a pattern:

- They start with a strong urge to perform the tic.
- The person then performs the tic.
- The person might also need to repeat the tic until it feels 'just right'.
- There is then a brief sense of relief before the person feels the urge to repeat the tic.

Performing these tics can be distressing and exhausting for the person with Tourette's and for people close to them.

Tourette's affects the body's nervous system. We don't know everything about what causes it. But it seems to be largely inherited. Other things we know about Tourette's include:

- Tourette's is much more common in boys than in girls.
- Tourette's starts in early childhood and usually peaks at about 10 years old.
- The symptoms usually become gradually less severe as young people reach adulthood.
- By early adulthood, only about 20 in 100 people with Tourette's will still have tics that cause them any problems.

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Tourette's often happens alongside other mental-health conditions. The most common ones are obsessive-compulsive disorder (OCD) and attention-deficit hyperactivity disorder (ADHD).

(For more information on these conditions see our leaflet on OCD and our various leaflets on ADHD.)

What are the symptoms?

Lots of young children have tics or habits that come and go. For example, children might rock themselves or make shapes with their fingers in repetitive ways. Or they might make regular, rhythmic gestures.

Children sometimes do these things as a way of comforting themselves, and most children grow out of them.

Tourette's syndrome is different. For a child to have Tourette's, they have tics that:

- are both vocal (sounds) and 'motor' (physical gestures), although not always at the same time
- are sudden, rapid, repeated, and not in a regular, rhythmic pattern
- may be less or more frequent over a period of time, but that have been going on for at least a year
- started before the age of 18 years
- are not caused by another medical condition, or by a 'street' drug.

You might hear your doctor talk about two types of tics: 'simple' and 'complex' tics. This really just means that complex tics last longer than simple ones.

For example:

- Simple motor tics tend to be brief jerking or twitching movements, whereas a complex motor tic can be a more complex gesture, or a series of gestures.
- Simple vocal tics tend to be brief sounds, while a complex vocal tic can involve repeating several words, echoing what someone else says, or swearing.

Your doctor will ask you questions about your child's tics to try to rule out causes other than Tourette's. For example, he or she might ask:

- what medicines your child is taking
- whether your child is under any stress
- (for girls) if the tics are worse during her menstrual periods
- whether your child has a health problem that might cause them to sniff or blink a lot. For example, some children with a certain type of asthma sniff a lot, which can be mistaken for a tic.

Your doctor should also ask about how your child is doing at school. If your child has trouble paying attention or focusing in class, it's possible that he or she has ADHD or OCD. These conditions commonly go alongside Tourette's.

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Your doctor should also ask about any other habits, phobias (fears), or unusual behaviours your child might have. He or she will also ask about any family history of Tourette's, ADHD, OCD, or hearing problems. All these things can help your doctor to make the right diagnosis.

What treatments work?

Things you can do to help your child

There are medical treatments that can help with Tourette's. But some of the best treatments are simple things you can do to help your child and yourself.

The first, and possibly the most useful thing you can do, is for you and your child to learn as much as you can about Tourette's. Understanding the condition can help you and your child feel more relaxed about it. And learning about it together can help your child feel that you are dealing with it as a team.

Other things that help children with Tourette's include:

- having a structured daily routine that includes lots of physical activity
- good sleep hygiene. This means having a regular bedtime, and a regular bedtime routine that is as calm as possible, and making sure your child is not over-stimulated at bedtime. For example, using devices with bright screens, such as mobile phones and tablets, close to bedtime doesn't help children to relax and sleep. You could try reading with your child at bedtime instead
- avoiding stressful situations as much as possible. Stress can make tics worse.

Of course, all these things are hard to do all the time - things will happen to disrupt even your best plans. You can only do your best. But getting into good habits can be a big help.

If your child is diagnosed with Tourette's you should make sure that his or her family members, teachers, and friends know about it. The more you can do to help the important people in your child's life learn about Tourette's, the better.

Medical treatment

Children with Tourette's usually only need any medical treatment if their tics are causing them distress.

For children who do need help, the first treatment that is usually recommended is called CBIT (pronounced 'see bit'). This stands for **Comprehensive Behavioural Interventions for Tics**. It is a form of therapy that, over time, helps people to manage their tics.

There are some medicines that can help some children with Tourette's. But they are not usually recommended unless CBIT has been tried without success, or unless it is not available.

The choice of medication usually depends on whether your child also has ADHD or OCD. This is because different medicines help with the different symptoms of these conditions.

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- Children without OCD or ADHD sometimes benefit from medicines that reduce anxiety, or from medicines called neuroleptics. Neuroleptics are usually used to help prevent hallucinations in people with a variety of psychiatric conditions. But they can help reduce Tourette's symptoms in some people.
- Children with ADHD are sometimes prescribed medicines that stimulate the body's nervous system, which helps them to focus and concentrate.
- Children with OCD can sometimes benefit from antidepressants. These drugs are usually used to treat depression, but they can help reduce the symptoms of OCD and the anxiety it causes.

All these medications can cause side effects in some children. Your doctor should discuss these with you carefully. Tell your doctor straight away if your child has any side effects from his or her medications.

Some parents try alternative medicines for children with Tourette's. But there is no good evidence that any of them work.

What will happen?

It's impossible to say what will happen to individual children with Tourette's syndrome. But the symptoms usually get less severe as children grow into adulthood.

In the meantime, treatments for Tourette's can help a lot. But it is a long-term condition with no cure. So your child might need regular follow-up to see how he or she is doing.

If your child is taking medication to help with the symptoms, your doctor will want to see him or her every few months to check if it is helping.

Tourette's symptoms tend to wax and wane (come and go, or at least get more or less severe) over time. If your child has a spell with mild symptoms, your doctor might suggest reducing his or her medication, and using it more when symptoms are worse.

You should regularly check with your child's school about how he or she is doing - but you probably know this anyway.

Teenagers with Tourette's are more likely than other people their age to suffer from depression. So this is something to look out for and to talk to your doctor about if it affects your child.

Adults with Tourette's can face problems in daily life, such as with further education and employment. And Tourette's often goes alongside other mental-health issues, such as depression, obsessive compulsive disorder (OCD), and attention-deficit hyperactivity disorder (ADHD).

So if you are an adult with Tourette's, it's important to try to get the treatment and help you need.

There are plenty of support groups for people with Tourette's syndrome. Your doctor might be able to direct you to one in your area, or you could look online.

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