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Tourette Syndrome

If your child has Tourette syndrome, learn all you can about it. Your child can get help.

What is Tourette syndrome?

Tourette syndrome (toh-RETT SIN-drum) is a medical problem that affects behavior. People with Tourette syndrome make movements and sounds that they can't control. These are called **tics**.

Deaf children can have Tourette syndrome, too. Mostly boys have it. But girls can have it, too.

Different kinds of tics

There are 2 different kinds of tics: **motor tics** and **vocal tics**.

Motor tics are movements:

- eye blinking
- nose twitching
- head jerking
- facial grimacing (making strange faces)
- jumping
- sniffing
- pounding on chest
- spreading fingers apart

Some people have motor tics that involve hurting themselves, like biting their tongue or hitting their head on a wall. But this is rare. Most people with Tourette syndrome do not have this kind of tic.

Vocal tics are sounds:

- throat clearing
- tongue clicking
- yelping or barking
- repeating someone else's words
- saying (or signing) bad words without a reason (But most people with Tourette syndrome don't do this)

When your child may have tics

Tics can start during childhood. But they can also start during the teenage years. Some people "outgrow" many or most of their tics. But some don't.

Your child may have more tics when he's stressed. But there are times when the tics can get better:

- When your child is relaxed. Like when he's watching TV.
- When your child is focusing on something that he enjoys. Like doing a jigsaw puzzle or reading a book.
- When your child is asleep. Tics usually get a lot better or go away completely during sleep. But not always.

Many children with Tourette syndrome also have [problems with attention and focus](http://www.raisingdeafkids.org/special/adhd/) (<http://www.raisingdeafkids.org/special/adhd/>). Many have [obsessions and compulsions](http://www.raisingdeafkids.org/special/ocd/) (<http://www.raisingdeafkids.org/special/ocd/>), or act in a very rigid way. Some have [learning disabilities](http://www.raisingdeafkids.org/special/ld/) (<http://www.raisingdeafkids.org/special/ld/>).

What causes Tourette syndrome?

Doctors don't know what causes Tourette syndrome. But it does run in families. So if one of a child's parents has Tourette syndrome, the child has a greater chance of having it.

Sometimes a parent with Tourette syndrome has a child who does not have Tourette syndrome, but has a similar problem. Like [obsessive-compulsive disorder \(OCD\)](http://www.raisingdeafkids.org/special/ocd/) (<http://www.raisingdeafkids.org/special/ocd/>) or [attention deficit-hyperactivity disorder \(ADHD\)](http://www.raisingdeafkids.org/special/adhd/) (<http://www.raisingdeafkids.org/special/adhd/>).

What the signs of Tourette syndrome are

People with Tourette syndrome makes sounds or move in ways they can't control. So the signs are pretty easy to notice. But watch out for early warning signs that your child has this syndrome.

There are almost always signs of Tourette syndrome before age 21. The first signs are usually between ages 5 and 11.

Early signs

- Simple motor tics in the face. Like blinking their eyes over and over again. Or twitching their nose.

Later signs

- More complicated motor tics. Like jumping or stamping their feet.

You might notice that your child "tics" more at certain times, or at certain places. Often, children try hardest to hide their tics at school or other public places. But they may "tic" a lot at home, where they feel safest.

There is no cure for Tourette syndrome. But the tics often get better as the person gets older. The tics don't usually go away completely, for the rest of the person's life.

Sometimes they go away for a few months at a time, and come back when the person has more stress in his life.

Some people with Tourette syndrome can learn to control their tics a little bit. They may be able to stop themselves from having tics when they don't want to have them, like in a classroom or at a meeting. But they can't stop the tics completely. And the tics might be worse when they finally do have them. It's like trying to stop yourself from sneezing. You might be able to stop yourself from sneezing for a few minutes, during a speech or a concert, but in the end you'll still need to sneeze.

How to find out if your child has Tourette syndrome

Your doctor will be able to see if your child does by asking questions and watching your child. So take your child to a doctor. Bring notes on what and how often he does these things.

The doctor will ask you some questions:

- What your child is doing. The doctor will also watch your child. But remember, your child may try hard not to show his tics in the doctor's office.
- If anyone else in your family has Tourette syndrome. (Often adults have forgotten they had tics as a child, or they are embarrassed to tell. So you may not know if anyone in your family had Tourette syndrome.)

Your doctor might do tests on your child to rule out other problems:

- MRI
- A CT
- EEG

Deafness does not cause Tourette syndrome! If your child is getting teased or having trouble in school, and you think tics might be part of the problem, keep trying until you get help for your child!

How you can help your child

People usually don't take medicine for Tourette syndrome. That's because the symptoms of Tourette syndrome (the tics) don't usually get in the way of the person's life. Kids with Tourette syndrome can usually do all the same things as kids without it.

Medicine

But when the tics are bad enough to get in the way of life, there are medicines that can help. There is more than 1 medicine available. But no single medicine makes the tics go away completely. And they all have some side effects, like making your child more tired or making his stomach hurt. Ask your child's doctor whether your child should take medicine.

Getting counseling

You might have to take your child to a psychologist, psychiatrist, or neurologist to get more help. Sometimes children need counseling as well as medicine to help these problems. Make sure the help your child gets matches the problems he is having. Don't assume that the problems will go away on their own. But don't be afraid that the problems will last forever, either. They are usually temporary.

If your child has a hearing problem and also has Tourette syndrome, make sure the doctors that help your child with the Tourette syndrome also know about deafness. If your child uses sign language, try to find a doctor who knows sign language. Ask the doctor and the counselors at your child's school to help you find someone who knows about both deafness and Tourette syndrome.

Helping your child at school

Make sure your child's teachers know that your child has Tourette syndrome. [It should be written on his IEP](http://www.raisingdeafkids.org/learning/rights/iep.jsp) (<http://www.raisingdeafkids.org/learning/rights/iep.jsp>). That way, they will understand why he has tics that he cannot control. They will not get mad or punish him when the tics happen.

Your child might have some trouble making friends if the other kids at his school don't understand why he acts "differently" from them. It could help your child to meet other kids with Tourette syndrome. This will show him that he is not alone. It will also help him meet kids who share and understand his problem. [To look for support groups in your area, click here](http://www.tourettesyndromesupport.com/localsupport.html) (<http://www.tourettesyndromesupport.com/localsupport.html>).

Learn more about Tourette Syndrome

- [Tourette Syndrome Association](http://www.tourettesyndromesupport.com/localsupport.html) (<http://www.tourettesyndromesupport.com/localsupport.html>)
- [KidsHealth's page on Tourette syndrome](http://www.kidshealth.org/parent/medical/brain/tourette.html) (<http://www.kidshealth.org/parent/medical/brain/tourette.html>)
- [National Institute of Neurological Disorders' "Tourette Syndrome Fact Sheet"](http://www.ninds.nih.gov/health_and_medical/pubs/tourette_syndrome.htm) (http://www.ninds.nih.gov/health_and_medical/pubs/tourette_syndrome.htm)

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You can find this page online at:

<http://www.raisingdeafkids.org/special/tourette/>