UNDERSTANDING YOUR DIAGNOSIS

Tourette Syndrome

Also called Tourette's Disorder

Tourette syndrome means your child has sudden movements and sounds, called tics, that they cannot fully hold back.

HOW COMMON	OFTEN STARTS	USUALLY PEAKS	GOOD NEWS
About 1 in 160 children	Between ages 4 and 6	Around ages 10 to 12	Most improve by adulthood

What this is

- Tics are sudden movements or sounds the body makes without full control. Tourette syndrome means both kinds have lasted over a year.
- Tics are not done on purpose and not attention seeking. Punishing them does not work, because your child is not choosing them.
- Swearing out loud is what movies show, but it happens in only about **1 in 10** people who have Tourette syndrome.
- Most children with tics do well. The hardest parts are often other people's reactions and the conditions that come alongside.

What it can look and feel like

- Simple tics come first, usually eye blinking, face scrunching, head jerks, or shoulder shrugs, and they shift over time.
- Sound tics include sniffing, throat clearing, grunting, coughing, or repeated words. Parents often think it is allergies at first.
- Older children describe an itchy, building feeling before a tic, and relief right after. That urge is what drives the tic.
- Your child can hold tics in for a while, especially at school, then let them out in a burst as soon as they get home.
- Tics get worse with stress, tiredness, excitement, and illness, and often ease off when your child is absorbed in something.
- Tics come and go. They can vanish for weeks and return looking completely different, and that pattern is normal.
- Trouble with attention, or repeated worries and rituals, is common alongside tics and often bothers children more than the tics.

What is happening in your brain and body

- Brain circuits that filter out unwanted movements do not brake as strongly, so extra movements slip through as tics.
- Dopamine, a brain chemical involved in movement and reward, is overactive in those circuits. Medicines that turn it down help.
- The area that gets movements ready is less well controlled, which is what makes the build-up feeling so insistent.
- Tourette syndrome runs strongly in families. Genes explain most of it, though no single gene causes it by itself.
- Tics usually peak around ages **10 to 12** and then settle down as the brain keeps maturing through the teen years.

What can make it more likely

- Genes are the main reason. Tics, attention problems, and repeated rituals often show up across the same family tree.
- It comes from how brain circuits develop before and after birth. Nothing you did as a parent caused your child's tics.
- Stress, short sleep, and excitement do not cause Tourette syndrome, but they reliably turn the volume up on tics.
- A few medicines, including some stimulants, can bring out tics in a child already prone to them. Tell your prescriber if that happens.

What to expect

- Tics usually begin around ages **4 to 6**, are at their worst in early adolescence, and improve for most people after that.
- By adulthood many people have mild tics or none at all. A smaller group keeps tics that still need treatment.
- Judge any treatment over months, not weeks, because tics naturally rise and fall on their own no matter what you do.
- Many children never need medicine. Good information for your family and your child's school is often enough on its own.

What helps

Treatment works. Most people get better.

Talking therapies

- **CBIT** is the first-choice treatment. Over about **8 sessions**, your child learns to notice the urge and use a competing movement.
- It works by helping your child get used to the urge instead of fighting it. The benefit lasts well after sessions end.
- Exposure therapy aimed at the build-up feeling is another option in specialty clinics and works in a similar way.
- If worries and rituals are also present, **exposure and response prevention** for those often helps more than treating tics.
- Teaching family and teachers that tics are involuntary lowers punishment, shame, and stress, and that lowers tics too.

Medicines

- Medicine is for tics that hurt, embarrass, or get in the way. Mild tics very often need no medicine at all.
- **Alpha-2 agonists** such as guanfacine and clonidine are usually tried first. They also help attention. Watch for sleepiness.
- **Aripiprazole** is approved for tics and works well, but it can cause weight gain, so weight and blood work get checked.
- Older antipsychotics also work but carry more movement and heart side effects, so they are used less often now.
- Botulinum toxin shots can quiet one stubborn tic. All doses are set with your prescriber, and changes are made slowly.

Everyday things that help

- Do not tell your child to stop. Holding tics in builds pressure and usually leads to a bigger burst a little later.
- Protect sleep and lower the pressure where you can. Tired, stressed days are reliably worse tic days.
- Ask school for tic breaks, a separate testing room, less handwriting, and a short talk for classmates if your child agrees.
- Watch for neck, head, or back pain from forceful tics, and tell your doctor if any tic is causing an injury.
- Connect with a Tourette support group. Meeting other families cuts shame faster than almost anything else does.

Get help right away if

- Your child talks about dying or hurting themselves. Call or text **988**, or go to the nearest emergency room.
- A tic that is injuring your child, such as hard head snapping, or any new weakness. Call your doctor today.
- Tics start suddenly in a teen with complex phrases, or a fever comes with new movements. Get seen promptly.

Questions to ask your care team

- *Are my child's tics bothering them enough to treat, or can we watch and wait?*
- *Should we try CBIT first, and how do we find a therapist trained in it?*
- *Does my child also have attention or worry problems we should treat first?*
- *What should the school know, and can you write a letter explaining tics?*

Where this information comes from

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NOTE

Sources are listed in APA 7th edition style. This handout is general health information, not medical advice, and it does not replace talking with your own doctor, therapist, or prescriber. Medicine choices and doses are decided with your prescriber. If you are in danger or thinking about hurting yourself, call or text 988 in the United States, or go to your nearest emergency room.