

When Your Grandchild Has Tourette Syndrome

"Surely, two of the most satisfying experiences in life must be those of being a grandchild or a grandparent." – Donald A. Norberg

You may have just learned that your grandchild has a diagnosis of Tourette Syndrome (TS). What does that mean? Will he or she ever get better? What treatments are available? How can you help both your grandchild, and their parents, handle this? What role can you play as a grandparent? We hope to answer some of those questions below.

[Learn more about Tourette Syndrome.](#)

Some key takeaways are:

- TS is a neurodevelopmental disorder that has a genetic basis.
- Coprolalia, or cursing, affects only a small percentage of those with TS
- It is no one's "fault" and is not a result of faulty parenting.
- TS is more than tics. Tics can be just the tip of the iceberg.

<https://tourette.org/resource/iceberg-illustration-poster/>

A significant number of children diagnosed with TS have co-occurring disorders, such as ADHD, OCD, learning difficulties, anxiety or mood disorders, behavior problems, sleeping problems, and social skills deficits.

<https://tourette.org/researchmedical/cooccurring-conditions/>

Motor tics and vocal tics may wax and wane over the course of a lifetime, and even over the course of a day. It's helpful to recognize that many tics are not obvious to others, such as tensing ab muscles or toes, and just because you didn't observe tics on a given day, that doesn't mean "they're all better" or "they will grow out of it." There may indeed be some good days and some less good days. Because tics can come and go, they can often be misunderstood as misbehaviors, e.g. Why does he tic while doing homework but not while playing video games?

You may wonder "can they control their tics?" While children may learn how to *manage* their tics and may even be able to suppress them for a short time, you cannot have the expectation that they "can hold their tics in if they want to." Reward and punishment are not effective methods to help children manage their tics. It's also not helpful to ask them to "just stop it" or "calm down." It's fair to assume that if they could, they would.

Also, for many children, calling attention to their tics in the moment can be a trigger that increases ticcing. Ignoring tics can be the best approach. That said, it's true that sometimes tics are hard to ignore. Try to respond neutrally, or even with a sense of humor! Laughter can be the best medicine. Recognize that symptoms may be less when a grandchild is with you. This is very common and doesn't indicate that parents are doing anything wrong. It may be helpful to let parents know that this is common.

Your adult child may feel guilty and wonder if they did something to cause tics to get worse. They may wonder if life stressors, such as having a baby, getting divorced, moving, and so on, caused the tics to appear or to increase. You can reassure your adult child that it's not their fault. Tics may indeed increase in stressful situations; finding ways to help your grandchild manage that stress, or finding ways to *proactively* help them reduce stress, can be effective.

So how do you do that? How can you help?

Offer to do research, educate yourself, share information, and just listen.

Your adult child may have their hands full. They may feel guilty about ignoring their child's siblings. You can offer to take your grandchild with TS to an appointment, or to take the grandchild and/or their siblings for a fun outing. Plan outings that can accommodate the tics—not places where they are expected to be quiet and sit still. When you give unconditional love to the grandchild with TS, and extra attention to the siblings, you also free up time for your adult child to do some self-care. If you live far from your adult child and grandchildren, consider a weekly scheduled phone call or video call, or offer to pay for a babysitter. Have your grandkids come to you for a visit to spend time with you alone and to create special memories.

Don't criticize.

A TS diagnosis may bring emotional, marital, and financial stressors to your adult child. Lend a hand without judgement. You may not agree with your adult child's child rearing practices, but your emotional support is vital to giving your adult child the strength to deal with your grandchild's chronic condition. Support their choices of treatment. There are no magic pills. They may need to try multiple kinds of therapies to see what works. Unfortunately, many treatment providers do not accept insurance; consider offering financial assistance if possible. Your adult child might be reluctant to ask for help.

Educate others.

Your friends, members of your church or synagogue, or people staring in the grocery store may be unfamiliar with the disorder. If you are asked "why are they doing that?" there is no shame in explaining your grandchild has tics or TS, in the same way you might not hesitate to explain if they had diabetes or a peanut allergy.

Get involved.

Show support for your child and grandchild and become active in Tourette Association of America activities. [Find your local chapter or support group.](#)

Take care of yourself, too.

You may feel sad, wish there was a cure, and worry about your grandchild's future. Remember that TS is only one aspect of who your grandchild is. There are successful athletes, doctors, actors, musicians, police officers, and teachers with TS. Encourage your grandchild's strengths and talents, but don't forget to take time for yourself, too. Reach out to the TAA or your local chapter when you need support.

A Tourette Syndrome diagnosis can be challenging for the whole family, including your grandchild, the siblings, your adult child, and you, the grandparent. Facing this challenge together, however, can make your family stronger and more resilient. As a parent and grandparent, you are a priceless resource for both generations.

***"Grandparents can be very special resources. Just being close to them reassures a child, without words, about change and continuity, about what went before and what will come after."* — Fred Rogers**