

Teen Guide to Tourette Syndrome and Persistent Tic Disorders



This toolkit is intended to be a guide for teens who are learning to navigate life with Tourette syndrome (TS). Many people mistakenly think of TS as just a childhood disorder because that is when tics often are most severe, but it is important to understand that TS can affect people of all ages. Being a teenager means having new challenges and opportunities. Your body and brain grow and change very fast, and how your Tourette affects you may also change. Teens face many life transitions and have much to learn and consider when living with TS. This toolkit is meant as a guide and resource to assist you when you face new experiences. In this toolkit you will find information on a variety of topics, including: the basics of TS and co-occurring conditions, managing doctor appointments, transitioning to high school and college, driving, and friendships and relationships.

TOURETTE SYNDROME: THE BASICS

- Tourette syndrome is a neurodevelopmental disorder, meaning a disorder that affects the nervous system and the brain. The first signs of Tourette begin in early childhood or adolescence. TS is part of a group of conditions known as Tic Disorders. There are two types of tics, motor tics, which are tics that involve movement, and vocal tics, which are tics that involve making sounds.

Here is some more information about types of tics:

TYPES	SIMPLE	COMPLEX
Motor Tics Some Examples:	SUDDEN, BRIEF MOVEMENTS: Eye blinking, head shaking, face grimacing, shoulder shrugging, abdominal tensing, or arm jerking	MOVEMENTS ARE OFTEN SLOWER AND MAY SEEM PURPOSEFUL IN APPEARANCE: Touching, tapping, hopping, squatting, skipping, jumping, or <i>copropraxia</i> (obscene gestures), <i>Coprographia</i> (involuntarily making vulgar writings or drawings. May happen on a video call, text or over social media).
Vocal Tics Some Examples:	SUDDEN SOUNDS OR NOISES: Sniffing, coughing, spitting, grunting, throat clearing, snorting, animal noises, squeaking, or shouting	WORDS OR PHRASES THAT OFTEN OCCUR IN AND OUT OF CONTEXT: Syllables, words or phrases (“shut up”, “stop that”), <i>coprolalia</i> (uttering of obscenities), <i>palilalia</i> (repeating own words), <i>echolalia</i> (repeating others’ words)

- Tic disorders are on a spectrum, with different labels used depending on the type of tics you have and how long you have them. Both motor and vocal tics are involved in getting a diagnosis of Tourette syndrome.
- A Tourette syndrome diagnosis is usually made by a neurologist, psychiatrist, or a developmental pediatrician. To receive a diagnosis of Tourette syndrome, the person needs to have had at least two motor tics and one vocal tic, not necessarily at the same time, for at least a year, and these tics need to start before the age of 18.
- Tic disorders affect many people: 1 of 50 school-aged children have Tourette syndrome or another persistent tic disorder
- Over time, your tics might change in type, intensity, frequency, and/or where on the body they are located. This increasing and decreasing and even coming and going of symptoms is common.
- Scientists are not yet sure how common Tourette syndrome is in adulthood. Most people with tics see improvements by late adolescence or early adulthood, but some people continue to have tics as adults, and for some the tics can be severe. Compared to children, most adults report that their tics are more stable and do not change much in terms of type, intensity, or body location. There is some new data that suggest for women, tics might stay around into adulthood more often than for men, but scientists still need to learn more to see if it's true.
- Even though tics aren't voluntary, they are affected by many things, including what's going on inside and around you. For example, tics can become more severe if you feel stressed, are bored, or get a lot of attention from others about your tics. Being around others that have tics sometimes can set tics off, too.
- We don't know what causes Tourette syndrome. Tourette syndrome tends to run in families, and studies have confirmed that genetics are involved, meaning that at least a tendency to develop tics might be inherited from your biological parents. Researchers are continuing to search for the specific genes and other potential factors that may cause TS.

If you would like to learn more about Tourette syndrome or find a doctor near you, please contact the Tourette Association at www.tourette.org or by calling **888-4TOURET**.

TREATMENT FOR TICS

Tics can be treated with medications or with Comprehensive Behavioral Intervention for Tics (CBIT). Both medications and CBIT can be helpful, but oftentimes, tics will still be present. For more information on CBIT view our resource guide at Tourette.org or here: [Comprehensive Behavioral Intervention for Tics \(CBIT\)](#)

Having Tourette is not the whole story: CO-OCCURRING CONDITIONS

TOURETTE SYNDROME

Tics are just the
tip of the iceberg



- It's very common for people with Tourette syndrome to have another condition along with Tourette - 5 in 6 people with Tourette have at least one other diagnosed disorder. For many people, the symptoms of the other conditions are more bothersome than the tics themselves.

- Here are the most common conditions that people with Tourette might have:
 - **Attention-Deficit/Hyperactivity Disorder (ADHD)** – ADHD is a brain-based disorder that affects people differently. People with ADHD might have trouble paying attention and staying organized. Some have trouble with impulsive behaviors and may act without thinking. Others may be overly active (they might feel hyper or have a persistent need to “be on the go”). Many have some combination of these symptoms. Often, people with ADHD report difficulties with focus, concentration, and executive function—the ability to organize, plan, and manage thoughts and actions. It’s important to know that having ADHD doesn’t mean that you can’t focus, it means that it can be difficult to direct your focus, particularly when you are doing things that might not be very interesting.

Many people struggle with attention some of the time, and the kinds of symptoms that go with ADHD can also have different causes. To find out if you have ADHD, you should consult a professional. Your healthcare provider can carefully assess your symptoms and provide a comprehensive diagnostic evaluation to see if you have ADHD and to see if it’s not something else. If you do have ADHD and Tourette syndrome, it’s important that you get help and support for both, as part of your treatment plan. The recommended treatment for teenagers with ADHD is to combine behavior therapy and medication and receive school support and intervention. When ADHD occurs with other conditions like Tourette, treatment, including medication, might need to be tailored to your specific needs.

If you experience difficulties with attention, some ways to manage may be to work with your school counselor or a resource room teacher to help with executive functioning skills such as organizing, planning, and working through multi-step directions. Make your family members aware that you are seeking more support so they can help as well. For more information view this resource from [CHADD ADHD and Tics or Tourette Syndrome](https://chadd.org/) or visit <https://chadd.org/>



- **Obsessive Compulsive Disorder (OCD)** Having OCD means having unwanted thoughts and feelings (obsessions) that you feel you need to respond to (compulsions). The unwanted thoughts, images, or impulses might happen over and over, feel intrusive and upsetting. The behaviors are often done to try to get rid of the unwanted thoughts/feelings. The upsetting thoughts are often fear or worry-based, but not always. Often in those with TS and co-occurring OCD, it's more like something is really uncomfortable or something "just doesn't feel right."
 - Many people have obsessive and compulsive symptoms some of the time. The diagnosis of OCD is made when the thoughts/behaviors happen for a long time, are time-consuming or severe, and/or cause you distress or interfere with living your day-to-day life. OCD can be treated with medication and a type of Cognitive Behavioral Therapy (CBT) called Exposure and Response Prevention (ERP).
- **Anxiety Disorder** - Being anxious is a typical part of life, especially in stressful situations like taking a test or public speaking. But when anxiety lasts a long time or becomes severe, it can be an anxiety disorder. Anxiety disorders can present themselves in a variety of ways, and they differ in severity. Anxiety may feel like intense, excessive, or persistent worry and fear around everyday situations. You may feel a fast heart rate, sweaty, tired, or experience rapid breathing. If you experience anxiety, you are not alone. It's important to know that for some people, anxiety can present as anger or irritability, and for some, it shows up in body symptoms like headache or stomachache, having trouble focusing, or sleeping. Some may try to address their anxiety through avoidance, which in the long term isn't helpful when the anxiety is triggered by something that cannot be avoided. When anxiety feelings become excessive and interfere with your daily life, we recommend seeking support from your healthcare provider.

To help with management of anxiety, get physical exercise daily, eat a healthy diet, practice good sleep habits, and consider using relaxation and mindfulness exercises. Scheduling engaging activities like clubs, hobbies, and spending time with friends and family can help build connections with others and reduce anxiety as well. If anxiety becomes problematic and impairs your everyday life, you can ask your doctor about Cognitive Behavioral Therapy and/or medication to help with treatment.

- **Other conditions that co-occur with TS:**
 - Learning disabilities
 - Autism spectrum disorder symptoms
 - Depression or mood disorders
 - Rage attacks
 - Sensory hypersensitivity
 - Behavior disorders

Some people with Tourette struggle with feelings of depression and hopelessness, and may have thoughts about wanting to harm themselves or even end their life. Early warning signs can include feeling empty, hopeless, trapped, feeling like there is no reason to live, or feeling like they are a burden to others. Other warning signs include making a plan or researching ways to die; withdrawing from friends; giving away important items; taking dangerous risks such as driving extremely fast; displaying extreme mood swings; eating or sleeping more or less; using drugs or alcohol more often; or engaging in self-injurious behavior. If you or someone you know is struggling with thoughts of suicide or experiencing these warning signs, help is available 24/7 by calling or texting 988 to reach the Suicide & Crisis Lifeline (previously known as the National Suicide Prevention Lifeline).





NAVIGATING YOUR DOCTOR APPOINTMENTS

Going to the doctor's office, whether as a return visit or for the first time can be overwhelming. Your doctor will ask you questions that will help guide your treatment. Regular appointments with your doctor are essential for treating new, ongoing, or recurring symptoms. To help make your visit successful:

- Write your questions and concerns down so you have them readily available for discussion.
- Teens have some rights to privacy in a doctor's office. It's normal to have questions and concerns that you can't just tell your parents, even if you get along with them. If there is sensitive information you want to discuss with your doctor, without your parent or guardian, ask for private time. This can be communicated to the nurse, assistant, or doctor, or written as a note and handed to someone in the office.

- Watch [Planning a Successful Doctor's Visit](#) on the [TAA YouTube](#) channel.
- Have a list of important medical information ready for your doctor such as medications or other medical providers.
- Being at the doctor can feel stressful. Consider using relaxation and/or tic management strategies prior to the visit if you are concerned about the visit leading to an increase in tic or anxiety symptoms.

SCHOOL WITH TOURETTE SYNDROME

Many teens with Tourette syndrome have either a 504 or an Individualized Education Plan (IEP).

- 504 plans are legal documents that allow you to have school accommodations. Accommodations mean that you still have the same learning goals as other students, but that the school will change how they present the information to you or how you show them that you mastered the material. A 504 plan is covered under Section 504 of the Rehabilitation Act, which is a federal civil rights law that ensures an individual cannot be discriminated against due to their disability. Your teachers and other school professionals will have a copy of the plan. Accommodations can include, but are not limited to, extended time on tests, breaks, testing in separate locations, the use of a calculator, notes provided prior to lessons, and preferential seating.
- An Individual Education Program or Plan (IEP) is also a legal document that falls under the Individuals with Disabilities Education Act (IDEA). Having an IEP means that your learning goals are tailored to your learning challenges. If you need additional school services like a resource room teacher, counseling, consultant teacher, or occupational therapy, you will get those through an IEP as well as receive any accommodations you need to be successful in school
- The best plans are the ones that work for you, that allow you to get help in areas where you need help, and at the same time provide you with enough challenges that you can continue to build skills and learn to do more things for yourself. Accommodations aren't about taking the easy way out. You have a right to have them; they are there to take any unnecessary pressure off and remove obstacles you can't deal with, so you can focus on the most important learning goals. If you need any support or assistance at school, such as testing accommodations or breaks, talk with your parents, guidance counselor or teachers. Let them know what you need and why. Try out strategies and observe whether they help or not, and don't hesitate to ask for tweaks and changes over time as you learn more about yourself.
- You can give your counselor and teachers the [TAA Educator's Guide to Resources and Support](#), available in PDF form on [Tourette.org](#) or you can request hard copies at support@tourette.org.

TRANSITION TO HIGH SCHOOL

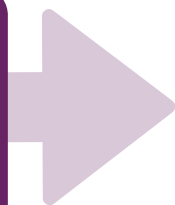
High school can be an intimidating, yet exciting time for all teens. However, having Tourette syndrome can often bring an added challenge. High school is a great time for you to learn to self-advocate.

- You may want to introduce yourself in an email to your teachers and let them know about your symptoms. If you have a 504 or an IEP plan you may want to let them know what accommodations are important for your success. Your teachers will read over your accommodations, however, as they have many students, it can be helpful to have an early conversation with them about what may be most helpful. This can also foster the start of a positive relationship.
- If you have a 504 or IEP plan, you should plan to be a part of the school and team meetings. Your opinion on what works best for you will be important to your success.
- If you need accommodations that are not on your 504 or IEP plan, or if you do not have one, let your family and a guidance counselor know. They can help make sure that the accommodations you need are put in place.
- One of the reasons transitioning to a new school can be challenging is meeting new friends or peers who may not know about Tourette syndrome. There are a variety of options you can consider if and when you are considering explaining TS symptoms.
 - Educating your classmates and teachers about Tourette syndrome may make it easier for you.
 - Consider starting with disclosing your TS symptoms to your close friends. They can be part of your support system during this journey. You might also consider educating your peers about common TS symptoms, and/or specific symptoms you experience. Though many people can be reluctant or nervous about educating their peers for fear of being the center of attention or teased, often, the opposite happens. Many teens and young adults report a sense of relief, support, and confidence after letting their peers know that they have TS.
 - Many teens with Tourette syndrome and visible / persistent tics report feeling more comfortable with their classmates after a peer education presentation. Many even report tic reductions because their stress surrounding “peers finding out” decreases, and as such, they feel less socially anxious. You can reach out to support@tourette.org if you would like to arrange a student presentation.

Remember that each situation is unique to you.

Plan how you are going to disclose to your peers.

Think about how your symptoms affect you socially. If you do not think others are noticing your tics, or they are not affecting you socially, you may not need to disclose your diagnosis.



SOCIAL RELATIONSHIPS

- Friendships and other relationships are hard work. Creating and maintaining healthy relationships as a teen with Tourette syndrome can come with specific challenges. For some teens with TS, social communication skills can sometimes be a challenge.
- The most important part of improving one's social and communication skills is becoming aware of areas in which you may struggle.
- If you do have trouble in certain social situations, you can learn skills and strategies by meeting with a therapist or counselor, speaking with a social worker or occupational therapist, or asking for feedback from people you trust.
- It's also helpful to remember that sometimes anxiety about one's social skills can be just as problematic as struggling in social environments in the first place. In those situations, it is important to address the co-occurring anxiety.

BUILDING SOCIAL SKILLS

- If you struggle in social situations, it is important to regularly practice engaging in social communication skill building.
- Some examples of social communication skill building include:
 - Practicing open and honest ways of telling others you have tics
 - Using active listening skills
 - Utilizing "I" statements when clarifying or discussing emotions with others (e.g., "I felt confused and sad about what you said," vs. "You were confusing and made me sad")
 - Using mindfulness or relaxation techniques, such as deep breathing exercises, before entering stressful social situations.

DATING

- Dating can be just as scary as it is exciting. You may feel extra stress when deciding how or when to tell a potential partner that you have TS. Tics sometimes increase due to dating stress, and certain co-occurring conditions can make dating more difficult.
- Watch out for tendencies to avoid things. It's wise to carefully select where you go and whom you see, but watch to make sure that you don't

miss out. If it becomes a habit, avoiding public places because of your tics could prevent you from meeting people.

- Tourette syndrome can sometimes make dating more difficult. In general honesty is often the best policy. You will want to tell people about yourself and your Tourette only when you are ready, but being open and upfront sooner rather than later can help you feel more comfortable and ensure that others around you understand that your TS does not define you.
- Self-confidence is always important. Being confident in yourself is not easy, especially when you are a teen and still learning who you are, but it is something you can work on. Remember that you have qualities and interests that are important, and that you are not defined by your TS. Try being your own friend and praising yourself for your good qualities and look at your struggles as a work in progress. Everyone has their own struggles, and it can be helpful to remember that no one is perfect, despite what you may think.

DRIVING AND TOURETTE SYNDROME

- Many teens start driving as soon as it is permitted by law. But being able to get a driver's license doesn't mean being really skilled and ready to drive. This is especially true for anyone who has a physical or mental condition.
- Driving is a complex activity that requires you to do a lot of body movements in a coordinated way. You need to start, change, and stop different movements, you need proprioception, which is your body's ability to sense movement, action, and location; you need to scan the road and surroundings and understand what you see; you need to know what to pay attention to and what to ignore so you don't get distracted; you need to integrate what you see with what actions you take; and you need to make many quick decisions.
- For individuals with Tourette syndrome, driving can be a particular challenge. It is important to note that tics do not usually impair driving abilities. However, with severe tics, driving performance may need evaluation to prevent inadvertent self-harm or injury to others.

Examples of tics that *could* interfere with driving:

- Neck flexion and extension
- Frequent eye blinking
- Eye rolling and blinking for extended periods of time
- Shoulder shrugging
- Back tensing and arching
- Head nodding
- Self-injurious tics

Having another condition such as ADHD and OCD may also make learning to drive and driving safely harder.

- Studies have shown that drivers with ADHD have higher rates of car crashes compared to people without ADHD.
- Some people with OCD may have certain fears that make it difficult to drive.

The Tourette Association has created a [Law Enforcement Toolkit](#) that can be stored in your glove compartment for when you do start to drive. Within this toolkit is a card that can help you with any interactions that you might have with law enforcement, for times such as getting pulled over.



TRANSITIONS AFTER HIGH SCHOOL

It's important to plan for a career with work that has meaning to you and allows you to live independently and productively. You may decide to go on to college, enter a trade or technical school or similar career training, or join the military. If you are curious about joining the military, you may want to read an article from the TAA website on [Military Service and TS](#). Vocational Rehabilitation (VR) services can be helpful in preparing for, getting, keeping, or regaining a job. To find VR services in your area you can go to [Ed.gov State Vocational Rehabilitation Agencies](#).

TRANSITION TO COLLEGE AND CAREER TRAINING

- Unlike high school, where your parents may have helped advocate for your needs and accommodations, it will be important to self-advocate in college and career training.
- If you have a 504 or an IEP plan, your guidance counselor can request accommodations for you for college entrance exams like the ACT or SAT.
- If you need accommodations, you may want to meet with your college's disabilities office. Colleges are required to consider Tourette syndrome as a qualifying disability in the classroom.
- Colleges will require documentation and verification of your diagnosis, as well as specific information on accommodation needs.
- Additionally, extra financial and support resources for young adults with TS may be available through your state or local vocational rehabilitation programs.
- Many community resources exist to help young adults with Tourette syndrome in finding ways to meet their goals and live meaningfully. For more information on these resources, you can visit your local vocational rehabilitation office or a [TAA Center of Excellence](#).

KNOW YOUR RIGHTS

- TS is recognized as a qualifying disability under the [Americans with Disabilities Act](#) (ADA).
- People with TS are sometimes discriminated against despite managing their symptoms and not posing any threat to themselves or others.
- Individuals with TS have the right to:
 - Receive fair housing
 - Receive appropriate educational and testing accommodations
 - Receive fair consideration for hiring and promotions
 - Receive reasonable accommodations in the workplace
 - Travel by plane without harassment due to tics
 - Use other forms of public transportation without harassment
 - Maintain employment for which they are qualified, and not be fired solely due to their diagnosis

YOUTH AMBASSADOR PROGRAM

The Tourette Association's [Youth Ambassador \(YA\) Program](#) trains teens ages 12 to 17 to talk about Tourette syndrome, advocate for themselves and for others, and to educate their peers and younger children with accurate information about this often misunderstood diagnosis.

The YA Program offers:

- Leadership skill development
- Communication skills
- Advocacy training
- Community presentations
- The opportunity to speak to your congressional representatives on National Advocacy Day
- Mentoring opportunities

For more information about becoming a TAA Youth Ambassador please reach out to support@tourette.org.

Makhoul K, MD Jankovic, J MD Tourette Syndrome and Driving. Movement Disorders Clinical Practice. 2021, oi: 10.1002/mdc3.13225

Why do I act this way? Because I can't control it.

I have **Tourette Syndrome** - a medical condition. It causes me to make loud sounds, have twitches and say things I don't mean. Please understand that this is a medical condition and I cannot control my tics. Treatment for Tourette and tics is limited and there is no cure. Please be aware that my condition is covered by the Americans with Disabilities Act.

Visit tourette.org to learn more.



This publication was supported by the Grant or Cooperative Agreement Number, NU58DD005375-02, funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.



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