

# The School Administrator: Ten Things to Know about Tourette Syndrome

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Tourette Syndrome is a neurological disorder characterized by motor and vocal tics with an onset in childhood. As a school administrator, it is likely that you will encounter students with TS sometime in your career. Because TS is a spectrum disorder with a wide variety of symptoms, the Tourette Syndrome Association has prepared this brochure to help you work effectively with these students.

## 1) No Two Cases of TS Are Alike

If you've encountered one student with Tourette Syndrome it is very tempting to conclude that you'll be prepared for the next one—you're not. No two cases are alike and the range of symptoms is huge. Although the media tends to focus on individuals with severe symptoms, and specifically on those with coprolalia (the impulse to curse and/or say exactly the word(s) that are most inappropriate at that moment), there are many more individuals with other tics symptoms.

Some tics are verbal and some are physical. You may encounter a student who sniffs; clears his throat; nods her head; taps his shoe; jerks her elbow; punches the air; barks like a dog; repeats what has been said; makes silly faces; kicks, etc. There is no end to the variety and tics come and go in unpredictable phases. They can even be "contagious" in that one person may "pick up" a tic from another. Some tics are very simple while others are complex. Once you accept the premise that each situation is unique and changeable, you will be better prepared to welcome a child with TS into your school and train your staff.

## 2) Children with TS have Limited Control Over their Symptoms

Controlling tics is difficult. It takes a great deal of concentration and energy—energy that is siphoned from what the student needs to pay attention in class. It has been compared to the concentration involved in suppressing a sneeze or cough while in the audience of a quiet play or concert—which is something that most of us can relate to.

Adults with TS may be better at controlling their tics than children. Many say that they hold them in for hours at work releasing them in the privacy of their office, car or a bathroom stall. Children with TS may need to "let loose" on the playground during recess.

They may even need to run up and down the hall during class hours to shake the tension from their bodies. Understanding this will make life easier for the school's staff as well as the child.

TS also mysteriously waxes and wanes, when a child's symptoms seem to disappear and reappear it is tempting to look for understandable patterns. There may be no pattern to discern. A child may have "controllable" or negligible tics for long periods of time, but that does not necessarily mean he or she is "over" TS.

## 3) OCD is a Huge Complicating Problem . . . And It's Just the Beginning

Most people with TS also have co-morbid neurological conditions, such as attention deficit disorder (ADD), obsessive compulsive disorder (OCD), learning disabilities (LD), sensory integrations issues and clinical depression. Some are besieged with an alphabet soup of syndromes.

When people with TS and OCD are offered the hypothetical choice of a magic pill that could immediately cure one syndrome or the other, they invariably choose to alleviate the OCD symptoms. The obsessive thoughts and repetitive compulsions are very, very difficult to live with. And while depictions in the media may make the symptoms seem almost cuddly the reality is harsh.

When a child in your school has OCD they may feel a tremendous need to touch objects in a ritual manner. They may need to repeat words, finish a train of thought before a conversation can continue, or arrange pencils in a rigid configuration. There is no way to predict what will stimulate these obsessive thoughts and/or behaviors. It is important that adults demonstrate compassion as the other children will no doubt find these behaviors peculiar and the child will be singled out as "weird."

And OCD is just the beginning of the complications that have an impact on many school age children. TS

is often accompanied by other co-morbid conditions. Attention Deficit disorder or Attention Deficit Hyperactivity Disorder—with which you are most likely very familiar—make it difficult for a child to focus on the task at hand. This often causes impulsive and inattentive behavior, creating the discipline issue for a child with TS. The degree of impact of each of these co-morbid conditions will be unique to each child.

Some children have TS and learning disabilities with a wide variety of difficulties including visual and auditory processing problems, visual motor issues, and the entire range of specific learning disabilities. On top of that, the majority of children with TS have very poor handwriting. It's difficult to read when a child's eyes fail to track across a page. Poor handwriting can be the result of coordination problems. Sensory integration issues can also distract a student and school administrators must be aware of how all these conditions work together to increase the difficulties faced by these children in school.

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### 4) We're All Stressed Out

Stress and anxiety have an impact on all of us. Students with TS find that tic symptoms are increased during times of particular stress and anxiety. Test taking, choosing teams, school play auditions, etc.; all produce stress in students with “normal” neurobiological status. When a child is already combating tics and compulsions, the stress is ratcheted up by many times the magnitude. Teachers must be aware of this and some accommodations may need to be made such as waiving time limits on a test and/or testing in a separate, and quiet, location.

“Good stress”—the excitement we all feel in anticipation of a special occasion, such as a field trip or a particularly fun school assembly, can also cause an increase in tic symptoms. Knowing that this is a possibility and planning for it may help the child enjoy the event without the increase in anxiety.

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### 5) Get Everybody On Board

It is critical that everyone including teachers, cafeteria workers, bus drivers, substitutes, cross walk guards, coaches, guidance counselors and janitors, learn about TS and what it means to the individual child in the school. A hurtful, if well-intentioned, comment from a cafeteria worker or the failure of a bus driver to acknowledge the impact of TS can have a terrible effect on the child. Substitutes are particularly important as they assume the authority of the regular teacher and may have different ideas about discipline in a classroom.

If as an administrator, you encounter a teacher who lacks the flexibility to adapt to the needs of the student with TS, you may need to place the child in another class. This is both for the child's sake and for the entire class, too.

Training is critical for everyone in the school setting who comes in contact with the child with TS. This can be accomplished through an in-service workshop conducted by a volunteer from the local chapter of TSA or through the use of the TSA Curriculum Guide for Educators. The training sessions last between 45 and 90 minutes and are well worth the investment of time by all the participants.

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### 6) Bad Kid or Bad Symptom?

There is a difference between willful disobedience and uncontrollable behavior, but it is not always so easy to tell them apart. The area of discipline in the classroom is a loaded topic. Adding the wild card of behaviors that may be beyond the control of the individual child makes decisions that much more difficult.

Children with TS and associated disorders respond best to consistent discipline rather than periodic punishment. For example, the use of a “time out” in an appropriate setting allows the child to re-group and regain his or her self-control. It's important to note that these students may require more repetitions and examples of acceptable/appropriate behavior than other children.

One way to help distinguish when the student is genuinely unable to control his or her outbursts is to establish positive communications from the start. Most children will own their culpability if they feel that they are in an environment of trust. When they break the rules they expect to be punished. Communications are key.

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### 7) Parents are Ready to Do Battle

Some parents and/or professional advocates are ready to do battle at a moment's notice. It's important for teachers and school administrators to understand that the lioness protecting her cub is a frightening enemy. She's also a powerful ally. Unfortunately, many parents of children with TS have been through long, hard battles with schools and school systems. You may encounter them after they have been on the defensive for years and it's important that you do your best to set a professional and mutually respectful tone from the start.

In addition, many of these parents have, out of necessity, become very knowledgeable about TS, and about their own child's educational needs. Use them as a

resource and an ally. They often have a wealth of information from conferences, workshops and TSA that will help you and your staff understand this baffling condition. Respect their input and make sure they know that you are working with them to educate their children and not in opposition.

In contrast, you may encounter parents who deny the child's condition. He or she may not be willing to discuss the symptoms of the diagnosis with the school staff and may have unrealistic expectations about what the school can accomplish. You will have to work with this parent on behalf of the child.

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### 8) IEP, 504, the IDEA and All the Rest of the Numbers and Letters You'll Need to Know

The Individuals with Disabilities Education Act, known as the IDEA, guarantees that students with disabilities receive the education that they deserve and the accommodations that they need in order to receive it. Each time the law is renewed, portions of it are reevaluated. It is sometimes difficult for school administrators and teachers to understand the nuances of these changes and the impact they have on individual children. It's also difficult for parents who may or may not be equipped to parse out exactly how the changes in the discipline and accommodations portions of the bill affect their children with TS. It's best that everyone involved keep focused on the goal of finding the best way to educate the individual student, as interpreting legal language is a quagmire no sane school administrator wants to enter.

The Individual Education Program, IEP, and 504 Plans are tools for determining how best to educate these children. There are some similarities between an IEP and a 504 plan. Both are legal documents that, once completed, must be adhered to in a non-discretionary way by the school system. The IEP has more specific guidelines than 504 and is designed to provide the student with appropriate modifications of the curriculum. The purpose of the 504 is to provide the student with access to the curriculum.

The IEP has been the standard for delivering special education services to students who have a variety of disabilities including hearing or visual impairment, serious emotional disturbance, a specific learning disability, autism, traumatic brain injury or are other health impaired (OHI) according to IDEA. In a number of states, children with Tourette Syndrome are placed on IEPs under this latter category, OHI. This is entirely appropriate given that TS is a neurobiological condition caused by a chemical imbalance in the brain.

Using an IEP, the curriculum may be modified through changes in teaching strategies, the classroom/school environment, and the addition of related services and/or in other ways to match the student's specific and individual needs.

Section 504 criteria includes the presence of a disability that affects a major life activity which may include but is not limited to seeing, hearing, speaking, walking breathing, and learning. There needs to be a record of such impairment and the individual must be regarded as having the impairment. The school environment can then be modified to allow the student to have appropriate access to the curriculum.

For example, a child with significant tics may be allowed to leave class to go to the nurse's office to "release" tics. He or she may need a reduced homework load, class notes or a laptop computer for school and homework. These accommodations address specific difficulties in eye-tracking, handwriting, reading impairments, etc. While the curriculum is not actually changed but the child's access to it is different than the average student.

These accommodations can go a long way toward enabling a child with TS to succeed in school.

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### 9) Making Accommodations May be Necessary

As each child with TS exhibits very different symptoms—and copes with them with varied abilities—accommodations may be needed. The specific nature of these accommodations will come out of the IEP, etc. but it is important to understand the scope in advance. Some students can take a test in the room with other children, but his or her tics disturb the others in the class. While other students simply cannot take a test in a room with too much stimulation, i.e. other children scratching pencils on paper. These accommodations must be determined on a case-by-case basis.

Some of the very things that teachers do to excite the students in their classroom may backfire on the children with TS, i.e. rows of brightly colored decorations, intriguing toys and other distractions may simply be too stimulating for a child with TS and ADHD who needs to give his energy to focusing on one thing at a time. The child with TS may need a neat, quiet workspace in order to study at home and a neat, quiet workspace in order to participate in school.

Many people with TS also report that the hum of florescent lights, the whistle of air conditioners, glare and other external annoyances that most of us can ignore, become huge obstacles to concentration. In a perfect world, it would be simple to move the seats of

children with TS so they aren't adjacent to an air vent or to allow them to wear headphones to block out noise while not excluding these children from regular school activities.

In this, less-than-perfect world, accommodations are a balancing act between including the child in all school activities and organizing their experience so that they can participate on their own terms. This is often difficult, but it is the role of the school administrator and teachers to help find a way to enable these children to get educated—despite the challenges.

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### 10) Life is Not Fair

The average ten-year-old believes it is—or should be—and it's hard to tell a little girl that the child sitting behind her is being held to a different standard of classroom behavior, but it's true. A child mimicking the tics of a classmate is being disruptive, while the child with the tics can't be held responsible for the noise in the same way.

Teachers must understand this and communicate the variable rules to all the students in the classroom. A favorite phrase of teachers familiar with TS is—FAIR does not equal EQUAL. The other students in the class may not know it for many years, but taking this lesson to heart—and learning compassion for people who are different—will help them later in life.

Another area of unfairness is in coping skills. Some children with mild symptoms have a great deal of difficulty coping with the impact of their symptoms in social situations, while others with severe cases blithely go through life as if their symptoms were a complete non-issue. The capacity to cope seems to have little

or nothing to do with the actual symptoms and much more to do with the individual personality, family and the nurturing—or less than nurturing—environment in which the child grows up. School can provide a safe place for children with TS to develop the coping skills that they will need as adults.

Life isn't fair and it's a hard truth, for children with TS. School administrators with the necessary background can ease a child's path and create an environment in which all the students learn compassion and acceptance on differences.

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### In Conclusion

The role of the school administrator is critical in defining the way a school enables children with TS to learn and thrive among their peers. The administrator works with parents and the students, but most of all sets the tone for the teachers who reign in their individual classrooms. Haim Ginott, a teacher, describes the awesome responsibility of being a teacher.

“I've come to the conclusion that I am the decisive element in the classroom. It's my personal approach that creates the climate. It's my daily mood that makes the weather. As a teacher, I possess a tremendous power to make a child's life miserable or joyous. I can be a tool of torture or an instrument of inspiration. I can humiliate or honor, hurt or heal. In all situations, it is my response that decides whether a crisis will be escalated or de-escalated and a child humanized or de-humanized.”

For students with TS, school is a challenge that can be overwhelming or a wonderful place in which they can grow and succeed. School administrators can make a difference in the lives of these children.

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