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ABSTRACT

This parent and teacher guide considers discipline for children with Tourette Syndrome (TS) who have difficulty with behavioral compliance. Discipline is defined primarily as "training to act in accordance with rules," and is not punishment but involves teaching self-control and observance of societal expectations. Controversy and misconceptions about discipline are noted. Consideration is given to redirecting the child from undesirable behaviors which can occur with TS, such as the urge to spit or touch or grab other people's personal body parts. Ways to redirect the child from obsessive thought repetition are also addressed to help avoid the child's distress when saying phrases or words of an obscene or violent nature which stick in their minds. Practice in anticipating outcomes of behaviors can be helpful for the child with TS who has difficulty with impulse control and does not see the connection between actions and consequences. In addition to teaching the child the concept of cause and effect, children can be taught how to make choices and to accept consequences for them. Also important is providing the child with structure, direction, and limits regarding the expression of explosive anger. Included are brief annotations of three videotapes and three publications on TS. (SW)

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DISCIPLINE AND THE TS CHILD

**A Guide for Parents and
Teachers of Children with
Tourette Syndrome**

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Introduction

For the majority of children who exhibit mild symptoms of Tourette Syndrome (TS), the issue of discipline at home and at school may not require any special considerations. At home, many parents of children with mild manifestations of TS find no need to alter their expectations for their child's ability to follow the rules for appropriate behavior and to observe the limits set for them. They are able to parent their children with TS in a manner consistent with parenting their other, non-affected children. Similarly, in school, the structure and rules of the regular classroom are an appropriate setting for the child with TS and his* mildly invasive symptoms, provided he is with a teacher and students accepting of his unusual mannerisms or vocalizations. This is all to the good.

However, TS is a neurobehavioral disorder that can vary greatly from individual to individual in its severity, intensity, and implications for problematic behavior. This discussion is meant to offer helpful guidelines for those parents and teachers who are in a quandary about the issue of disciplining a child who has proven that a "regular" setting in either home or school is not sufficiently structured to foster behavioral compliance on the part of that child.

* The pronouns "his" or "he" have been used here to designate both "he" and "she" so as not to unnecessarily encumber the reader. It is recognized that females, too, may have Tourette Syndrome, though they are, in this case, the minority.

How can we tell when a behavior is an expression of TS as opposed to when it is simply unruliness? When should we intervene, and when should we allow the child to continue behavior which appears to be out of control? At what point should we start holding him responsible for his own actions? In short, how do we teach this child discipline?

These are fundamental and very pertinent questions most often asked by parents and teachers charged with the primary responsibility for raising and educating a child with TS to be a healthy, functioning adult.

What Is Discipline?

Discipline is defined primarily as "training to act in accordance with rules." Many people mistakenly think of discipline as being a matter of punishment; this misconception clouds the issue of what is, in actuality, teaching self-control and observance of societal and cultural rules. For a child with a lifelong neurological disorder involving impulse control, understanding and observing societal rules are very relevant issues.

Unfortunately, for some, teaching discipline to children with TS has become unnecessarily complicated. This discussion will attempt to clarify this issue for those parents and teachers in charge of teaching the knowledge of and observation of society's rules to children who, by the very nature of their disorder — one of control — are in greatest need of that knowledge.

Discipline and Self-Esteem

Having TS means coping with a very complex set of conditions. The accepted diagnostic criteria for TS describe only the tip of the iceberg; i.e. the observable criteria. While one can observe various manifestations of motor and vocal tics and rituals of a conscious, but involuntary nature in a person with TS, one does *not* observe all the other underlying and hidden neurobiological processes which have vast social and behavioral implications — not only for the

person with TS, but also for those who live and interact with him.

Currently, (due to parents and teachers sharing their observations with one another, as well as communication among researchers from various professional perspectives) it is known that obsessive-compulsive disorder (OCD) and attention deficit disorder with hyperactivity (ADHD) are very often related and complicating phenomena of TS. Also, we now realize that tics can occur in the thought processes as well as in the body. Furthermore, we recognize how vastly important it is for the child growing up with TS to have an understanding and united support system with parents and teachers working together, so that he may have the best chance of emerging into adulthood with that all-important sense of self-esteem. We know that it is a healthy sense of self that will help him shrug off the puzzled stares and taunts of others that may follow him throughout his life. A strong self-esteem appears to be the single all-important factor which will ultimately divide the triumphant survivors from those who never find their niche in society.

And yet, amid all the sophisticated research being conducted about TS, how much do we really know about instilling that sense of self-esteem? This observer submits that we know relatively very little about it, because in following our instincts to preserve self-esteem, we are often hesitant to offer appropriate guidance, fearful of wrongfully chastising a child for actions we suspect he might not be able to control. Ironically, it is that uncertainty, that fear of making a mistake in judgment which most often prevents us from giving the child with TS the guidance and structure – the discipline – he so desperately needs.

Imagine how it feels to live inside a body and be aware that it may at any moment erupt with involuntary jerks, noises and strange looking rituals. Not only that, but your mind seems to have a will of its own, going off on meaningless counting sprees or running over and over a phrase just heard in conversation. Inhabit that body and preside over that mind for a short time and one simple fact soon becomes apparent: the only difference between you and your peers

is an ability to **control**. Your body works properly, but only after it has satisfied its irresistible urges to jump, jerk, spin three times, and crow. With TS, your mind works, but only when it is temporarily satiated with counting, ordering and repeating. One must indeed have inordinate amounts of patience to co-exist with all these manifestations of TS!

And yet, if the individual is to grow into adulthood feeling good and confident, or at least okay about himself, with a healthy sense of self-esteem, then that is exactly what he must do with his symptoms on both the physical and mental levels: learn to co-exist. For as one grows and develops a personality within the context of his TS symptoms, whether medicated or not, the symptoms are gradually but certainly incorporated into his self-image. He would not be himself without his TS symptoms; they are a part of who he is. Though able to laugh and cry, to feel love, hurt and hope, the individual must do all those things working around his TS symptoms. The element that he does **not** have to help him contend with the rigors of life – frustrating as it may be, the element of which his neurological set of circumstances robs him – is the element of **Control**.

What more appropriate or loving gift, then, could nurturers of the child with TS give him than to return to him a degree of that control he lacks neurologically by teaching him the control involved in self-discipline? (Again, self-discipline here does not mean suppression of tics.) What could he value more, and what would be more helpful than teaching him how to live within the unspoken but accepted rules of society? No parent or teacher would argue about wanting for their child or student a life of social adjustment, satisfying relationships, and a fulfilling career. When you think about it, these things are achieved only by observing the rules for achieving them – the rules of living as a member of a society.

Having said that, it is unfortunate to note that the subject of discipline often becomes a debatable, complicated and controversial one, because the basic premises about the issue of discipline appear to be built on some popular misconceptions.

Misconceptions

A common misconception about discipline arises when we unnecessarily attach the connotation of *punishment*. At first glance, disciplining a child with TS may appear to mean punishing the child for having his TS symptoms. On the contrary, what is hoped to be achieved in disciplining this child is instilling in him a growing sense of responsibility for and self-control over his behavior in general – and particularly for those rituals, thoughts and tics that are socially unacceptable because they are dangerous or harmful to either the person with TS or to others.

The concept of discipline becomes complicated even more when we erroneously attempt to separate out the person with TS from the TS symptoms themselves. In the final analysis, asking whether a behavior is generated by TS or is, instead, purposefully generated is a moot question because:

- 1) Any behavior comes from the same individual, not from either his “TS part” or his “non-TS part,” and,
- 2) As far as society is concerned, unacceptable behavior is unacceptable behavior, regardless of its cause.

In order to live within our culture’s mores and thereby attain the acceptance they desire and deserve, people with TS **must** be able to distinguish, and over time, learn to **control** the expression of those impulses which are unacceptable. This can be accomplished either by deliberate symptom substitution, or by learning to become aware of one’s own potentially out of control situations, and creatively work around them.

Because of the complex, involuntary nature of TS, parents and teachers may be easily confused about how to address each episode of destructive, harmful, or otherwise inappropriate behavior. They may question whether or not to address the episode with the child or to simply overlook it one more time. While understandable from an adult point of view, think for a moment of how this ambivalence on the part of his

nurturers might adversely affect the self-confidence of the child with TS. The child who, because of his lack of impulse control, is so in need of feeling some sense of control in his life, finds himself in a never-never land of intellectually puzzled and emotionally torn adults who are hesitant to set and enforce limits, fearful of demanding that the child conform to a level of which he may be incapable. That atmosphere of uncertainty is ripe for the development of manipulative tendencies on the part of the child, which can eventually evolve into a full-blown personality/conduct disorder.

Quite simply, if we hope to adequately meet his needs, those of us in charge of rearing this child do not have the luxury of time to debate the question. To find his place within the larger society, this child needs to learn explicitly which behaviors his contemporaries view as okay, and which behaviors they don't. Surely he deserves the chance to be taught this distinction, and then guided through the practice of it.

Impulse Control Via Redirection

Since TS appears to be a disorder of the censoring mechanism governing impulses, some urges generated by TS may be socially offensive, or even physically dangerous. A rather commonplace example is the urge to touch or grab other people's personal body parts. Obviously, this act will not be well tolerated, and is likely to push others' acceptance of TS symptoms to the limits. Another symptom that many find offensive is spitting. Though a legitimate expression of a neurological disorder, behavior with negative social connotations requires special guidance from caretakers. This guidance requires a careful balance of:

- 1) Non-judgmental acceptance of the child as he is, regardless of the nature of his urges, and
- 2) Creativity in helping the child to brainstorm about an alternative behavior or adaptation of the behavior that will both satisfy the motor, vocal, or sensory urge, and yet not offend others.

For example, to satisfy the urge to touch others, it would be reasonable for the adult in charge to suggest the child with TS first ask permission of the person to touch them, and then to touch that person on the shoulder, arm or some other less private body part. In this way, the guiding adult is accepting the child, TS and all, and the child is acknowledging his urges, and learning to live with and accept his TS rather than holding it in. Further, through brainstorming creative options, the child is learning from the adult that others in society also have their right to be who they are, and to have their wishes respected.

With spitting, a very simple but effective solution might be for the child to carry with him a handkerchief or tissue, and spit into it. In this way, he is not judged by others harshly for something he cannot help, plus he is being considerate of the sensibilities and the rights of others in his culture.

As mentioned, sometimes TS urges can compel a person to behave in a way that may be physically dangerous to himself or others. In this case, the adult should be very practical in attempts to avoid bodily harm. Sometimes this may mean being creative in setting house or classroom rules for the child. For example, if the child has a compulsion to place his hand on a hot stove whenever he sees one, allow him in the kitchen only after the stove is turned off, or if he is allowed to cook, allow him only use of the microwave, and declare the conventional range off limits to him for the time being.

Caring parents and teachers never hesitate to intervene when there is the possibility of physical harm. It is important to realize that they have just as much responsibility to intervene when the danger is potential social or psychological ostracism. Otherwise we cannot expect him to emerge into adulthood with the necessary social skills to take care of himself, form relationships and maintain employment. The child with TS simply may not inherently understand that a given impulse is socially unacceptable, particularly given the high incidence of learning disabilities among the TS population. If his primary caregivers are, for whatever reason, negligent in teaching and

illustrating this distinction between socially unacceptable behaviors and acceptable ones on a continual and consistent basis, then that child is denied the opportunity to learn to live in harmonious relationship with his peers. In the long run, this may prove to be much more handicapping than tics, noises, rituals, and obsessions.

Obsession Control Via Redirection

Many children with TS are quite distressed when phrases or words of an obscene, violent or cruel nature turn over and over in their minds. They may subvocalize these phrases or just hear them relentlessly. Examples might be, "I hate God," or "Mom will die." Not realizing that such intrusive thoughts are common to childhood and because they are unable to control the repetition of them, children with TS may fear becoming "evil", and assume moral responsibility for their thoughts. To help ease his mind, it may be useful to frequently reassure the child that thought repetition may be an aspect of his TS symptoms, and encourage him to talk openly with you about the intrusive thoughts he has that may frighten him. Talking about them and just acknowledging that they exist will help to demystify them and make them less scary. It may also be useful to suggest a more pleasant phrase with a more pleasant image to substitute and repeat. Rather than repeating "I hate God," substitute "I love God," or "I hate cod." If the child is of sufficient maturity to distinguish between humor of an affectionate, accepting nature and hurtful teasing, humor is always appropriate when dealing with the symptoms of TS.

Teach Cause and Effect

Disorders of impulse control affect how a child reasons and thinks. Often to his parents' and teachers' exasperation, this child truly lives for the moment. Though he may be of normal or above-average intelligence, foresight and thinking ahead to anticipate consequences are not often a part of this child's thinking processes. Therefore, often he truly fails to feel any responsibility for his own actions. He is not

necessarily being purposefully irresponsible; he simply doesn't see the connection between his actions and their consequences. Yet some degree of foresight and anticipation must be cultivated and practiced through the formative years in order for the child to mature into an adult who is capable of taking responsibility for his actions and his choices. What nature has not provided neurologically, teachers and parents can and must supply externally. Children may have to be told repeatedly and shown how their actions and words will prompt responses from others. This is not a population for whom one illustration will ever be enough.

Practice in anticipating outcomes of behaviors can be incorporated informally into daily casual conversation. For example, a parent might ask, "What do you think might happen if you leave the lid off the peanut butter jar?" After the child is directed to brainstorm alternatives such as, "The peanut butter would dry out," "Ants would get in it," or "It would be ruined," the parent might then ask the child to choose the desired outcome, (salvaging the peanut butter,) and then guide him through the steps to bring about that outcome, (replace the lid.) In short, the child must be taught, through practice and more practice, the reasoning process that those of us without problems of impulsivity take for granted. In order to be most effective, this exercise can be practiced as an ongoing family game of sorts — and not just in the moments after a minor disaster has occurred.

Another example might be a teacher nonjudgmentally asking an overly-active student — before he is instructed to line up for lunch — "What might happen if you were to push the person standing in front of you in the lunch line?" The student might respond, "He would push me back," "I might knock him down," or "I would get sent back to the room and have to eat lunch by myself." As with the parent, the teacher can ask the child to choose the desired outcome from the various alternatives, (eating lunch in the cafeteria with no problems,) and then guide the child to bring about that outcome; ("Then don't you think it might be a good idea to put your hands in your pockets, so you won't forget to keep them to your-

self?") Again, the child is guided through the reasoning process, and given the opportunity to make a pre-considered choice about his behavior. In this way, his self-esteem is not threatened, because his actions had been considered before they occurred. Many times, this preventive approach can avert a catastrophe. Over time, through continuous practice, this process will teach him by illustration that his actions always have consequences.

Moreover, as he matures, he will begin to realize that he has some degree of control over what happens to him and how he is treated by others. This is not a concept that a child with impulsivity problems can sense inherently. For this reason, he desperately needs our consistent, ongoing guidance in demonstrating that there is indeed a relationship between his *choices* of behavior, and how others treat him.

Teach Responsibility for Choices

As an outgrowth of teaching the cause and effect concept, children can be taught specifically how to make choices and to accept the consequences for their choices. As with other behaviors, this will take time, demonstration and practice.

Initially, offer only two alternatives, such as, "Would you like to work with the group in math today, or work the problems at your own pace at your desk? If you work with the group, you will be expected to complete the whole page of problems, and you will get a sticker when they're finished. If you work by yourself, you will be expected to do only problems one through ten, but no sticker. Which do you choose?" The choices may have to be repeated, but a time limit should be set for making the decision, possibly using a timer. Whatever the child chooses is implemented, with no argument or discussion tolerated from him at any point in the process. Allow him to either endure or enjoy the natural consequences of his decision. Though this approach sounds rigid, remember that you are trying to provide the child with a mental structure and order -- the cause and effect reasoning that he does not inherently possess.

Similarly, parents might ask, "Would you like to do your homework now and then watch television after supper, or would you like to go out and play now, and do homework after supper? Remember, if you choose homework later, there will be no television tonight." Then firmly implement the child's choice, to the letter, and refuse to engage in discussion or argument of terms at any point. If the child refuses to hold up his end of the bargain, then privileges may be revoked at the appropriate level. The point is to let the natural consequences of his decision stand as the rule.

If practiced consistently over time, the child begins to realize that he can take you at your word, and will feel secure in knowing what to expect from the environment. This sense of security will ultimately nip a great deal of oppositional behavior in the bud, though it may take many repetitions and attempted arguments from the child before he learns to trust the process. This will require, at times, the patience of a saint and the endurance of a marathon runner on the part of the caregiving adult. Parents and teachers must not fail to give themselves well-deserved congratulations for their perseverance!

Control of Explosive Anger Via Redirection

Perhaps the most problematic and misunderstood aspect of both TS and ADHD is the very real phenomenon of explosive, out-of-proportion anger. Stemming from the same organic source as mental impulsivity, explosive anger can override the better judgment of a child or adult with little apparent provocation. This, too, is neurologically based and generally accepted by those who live in close proximity to someone with TS or ADHD. It is often referred to as "having a short fuse." However, structure, direction and limits in its expression must be set during childhood if this problem is not to become a major handicap in building relationships and maintaining employment as an adult.

It has often been suggested that a punching bag be installed in the child's room to provide a physical outlet for aggression. However, unless the child car-

ries a punching bag with him day and night, this is pretty much a useless solution, because explosive anger of this kind will not wait until the child is able to reach his room and his punching bag. Such is the lightning-quick nature of the anger response that comes with a disorder of impulse control. The individual is literally incapable of waiting for a proper time and place to express it. Again, his neurology doesn't give him that choice.

To compensate and return what sense of self-control he still has available, we can teach him to direct his anger in ways which will bring about the least harmful consequences. For example, if, when in a rage, he senses that something is going to be broken, it is possible to be taught to have the presence of mind to reach for the plastic dishes instead of the French lead crystal. The crystal is off-limits as far as an acceptable expression of anger is concerned. Period. If the limits are violated, then privileges could be revoked, with the "penalty" fitting the "crime." Each family can discuss explicitly with the impulsive child (and his siblings) its own list of off-limits actions for expressions of anger.

This process involves recognizing the direct relationship between cause and effect referred to earlier, and will likewise take time and practice to perfect. However, it will be well worth the effort when we consider the alternative of out-of-control adult anger. For his own good, we must put limits on how, and for how long, a child is allowed to express his anger. Then we must see that those limits are enforced. Because of the neurology involved, he may find himself going over and over a perceived injustice, unable to let go of the persistent thought. When, after an explosion of anger, we help him to structure his fury by setting a time limit on its expression, and then kindly but firmly help him to redirect his attention and energies elsewhere, we are giving him a most valuable coping tool. For example, "You have spent thirty minutes now being angry because Michael didn't invite you to his party. I can surely understand your feelings; you're justified in feeling hurt. I'm sorry that happened, but now it's time to put it behind you. Right now I need your help in putting

away the groceries. Come with me." Then insist that he does, physically taking his hand and leading him away, if necessary.

For obvious reasons, this child may be extremely upset by not feeling "in command" of his own behavior, and therefore may become quite defensive when given an order or assignment. When told to do something, he can very easily be made to feel inferior and subservient, and take the whole thing as a personal affront — a situation which may spark an explosion of impulsive anger and frustration. For this reason, it is very helpful to monitor **how** our parental and educational commands, requests, suggestions and rules are stated. By using tactful language and short, structured assignments, we can foster compliant behavior and still allow the child a feeling of control over his own actions. This sense of control, as we've seen repeatedly, is tenuous and something that should be protected and nurtured whenever appropriate. It can be maintained with thoughtful wording.

As an example, if a well-meaning parent should say, "If you don't have your room cleaned by noon, you can't go to the movie," he or she is unknowingly waving a red flag in front of a bull. Why? Because the command is stated negatively, using the words "don't" and "can't." This emotionally volatile child will probably focus on those negatives and not even hear the rest. Furthermore, he can easily be overwhelmed with frustration and disintegrate into tears or rage at the prospect of a task like cleaning his room, because quite simply he may not know how or where to begin a task that has so many components. He literally feels incapable of the task. Though it may look like willful noncompliance or laziness, we must remember that incoming information doesn't organize itself in the brains of these children the way it would in a child without a disorder of impulse control. So what can be done?

Instead, try saying, "I'll bet you can get all your clothes off the floor and hung up in five minutes. I'll time you. Go!" After that segment is completed with your verbal coaching, ask, "How long do you think it will take you to make your bed? Let's see, Go!" Throughout the process, give plenty of positive, en-

thusiastic feedback. Then when the task is completed, say the equivalent of, "Since you did such a great job on your room, and saw the job through to the end without arguing or complaining, I think you deserve to go to the movie this afternoon." By breaking either domestic or academic tasks into segments, putting them in sequence, and outlining time limits, we are able to transform a potentially overwhelming task into a series of achievable activities. And by gently eliciting the child's cooperation rather than issuing strict orders, we do not put him on the defensive and threaten his shaky sense of independence and competence, but instead we build on it.

Over time, if consistently practiced, the child will gradually begin to approach tasks in this manner on his own, and it will evolve into his own strategy for approaching tasks as he grows into adulthood. Admittedly this takes much time, attention and repetition initially. It also requires dedication, belief in the child, patience, energy and resilience. However, when we consider the alternative of the child growing into an adult who, without our intervention, will likely have to daily face his own rages, noncompliance, and overwhelming frustrations, living in isolation, what choice do we really have?

Summary

In summary, to adequately serve these children as parents and teachers, it is our right, responsibility, and duty to provide support in basically two ways. First, by allowing and accepting the expression of tics, noises, and other urges which are not of a dangerous nature in either a physical or a social sense, we show the TS child acceptance and support. Sometimes, this may require us to try and simply tune out or overlook continual noises or movements that may grate on our nerves. In showing this acceptance of his neurological disorder as an intricate and unique aspect of his personhood, we give him a sense of "okayness" which is absolutely necessary in building the self-esteem he will certainly need to keep plugging away daily, despite the considerable annoyances that having TS can bring.

Secondly, we must also not be afraid to offer structure, direction, and the caring counsel of distinguishing right from wrong, appropriate from inappropriate; we must not be afraid to discipline. By providing this much-needed guidance in directing his energies and impulses, over time this will give him the knowledge and self-confidence that he *can* function autonomously, without us there, in any social situation.

All children need to have explicit limits set for them. Though they may balk and complain at the time, knowing the parameters within which they are expected to operate gives them a sense of security. Children with TS and/or ADHD are first and foremost children, and in that sense not very different from others as far as their needs for parenting and nurturing are concerned. They may, however, require many more repetitions and examples, more extensive and explicit demonstrations of appropriate behavior, more encouragement in seeing a task through to the end, and more short-term and concrete rewards for making progress than their peers. However, the reward of witnessing a child once considered "at risk" function happily on his own, confident in his abilities and in his future, is second to none.

Ramona Fisher-Collins has a bachelor's degree in special education, learning disabilities, and a master's degree in special education. She currently teaches a self-contained class for elementary school children with behavioral problems in Oklahoma City, OK. For the past ten years, she has conducted research on the school problems experienced by children with TS. Ms. Fisher-Collins serves on the TSA National Board of Directors.

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ADDITIONAL RESOURCES

VHS FILMS

An Inservice Film For Educators—A new aid for teachers to help understand the complexities of teaching children with TS. Includes explanation of the complexities and suggests interventions that work. 45 min.

Tourette Syndrome: The Parent's Perspective - Diplomacy in Action — Features E. Collins and R. Fisher-Collins providing guidance to TS families on school advocacy issues. Concrete suggestions to insure the success of the TS child's school experience. 45 min.

Talking About TS — Dr. Orrin Palmer (who has TS) leads an in depth discussion with a brother and sister, both of whom have TS. 45 min.

LITERATURE

Tourette Syndrome and Behavior—Drs. R. Bruun, K. Rickler and E. Kelman-Bravo, CSW,MS. 1991. Describes recent research and what is now known about the relationship of a variety of behaviors and TS. Contains helpful advice about the management of problem behaviors for families and individuals with TS. 21 pgs.

An Educator's Guide to Tourette Syndrome—S. Bronheim, Ph.D. Covers symptoms, techniques for classroom management, attentional, writing and language problems. 16-pgs.

Coping with TS—A Parent's Viewpoint - E. Shimberg. Covers parental and family acceptance, behavior management. 23 pgs.

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