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Tourette Syndrome • OCD • ADHD  
Sensory • ODD • IED/'Rage'

**Publishing:**

*Nix Your Tics! Eliminate Unwanted Tic Symptoms:  
A How-To Guide for Young People*

## AN EDUCATION IN EDUCATION

While my first TS convention exposure was phenomenal in every facet, there was one particular aspect which repeatedly overwhelmed me almost to the point of tears. You, the parents. Parents, taking the time and money out of their schedules to not only attend the annual conference, but to regularly attend meetings throughout the remainder of the year. Parents, taking leaves from their legal practices to better understand and work with their Touretic children. Parents, participating in the TSFC at both the national and chapter levels, writing articles, and raising money for, and awareness of, the TSFC. Remarkable. Positively extraordinary. Reader, if you are a parent, take a moment to put down this article and applaud yourself. Allow yourself to be enveloped in a warm glow of positive accomplishment because you ARE making an incalculable difference. Simply by being a part of the TSFC and educating yourself about TS is having an ENORMOUS impact in the life of your child. I want to suggest to you that the greatest gift that you have bestowed upon your TS child is providing him/her with an environment rich in information about TS.

I have no doubt that it may be difficult for some of you to see that: after all, your child(ren) may at this very moment be systematically dismantling his/her room. But consider this: because TS *is* a known quantity within your household, you don't know what life would be like (for either your child or you) if it wasn't. This article is intended to show you how much you, and your education in TS, has helped your child(ren).

Parental acceptance and understanding cannot be overemphasized or over-appreciated: they are crucial in the development of your TS child(ren)'s self-worth and esteem both as direct influences, and as mediators. First, directly: Charles Cooley spoke of the "looking-glass self", which consisted of a.) the imagination of our appearance to the other person, b.) the imagination of his judgment, and c.) some sort of self-feeling. In essence, how we feel about ourselves is largely determined by our perceptions of others' reactions to us. As the earliest and most prominent figures in a child's life, parents are integral to an individual's earliest foundations of self-concept. Many researchers since have maintained that one's relationship with one's parents is the single most important aspect in the development of self-worth. Simply by anticipating, recognizing, and accepting the Tourette's in your child(ren) you are implicitly communicating to him/her that they are a person worthy of positive regard and respect, regardless of their disorder. This message will become an ingrained part of their persona as they mature, thanks to you.

Parents have many indirect effects on their child(ren)'s self-worth as well; the educated parent makes those indirect influences worthy ones. Self-acceptance, good social conduct, and good self-control over negative affect have all been found to be fundamental to high esteem. All three of these life facets can be severely compromised by TS; self-acceptance is low because (s)he is different and may not fully understand those differences, and social conduct and self-control is abysmal due to impulse-control and disinhibition problems.

Parents with an education in what TS is possess a special tolerance for the condition. They may help to offset all of these accrued negatives: by displaying their love and understanding for their child, self-acceptance is improved. Knowing that the TS may be hindering social interactions (both because TS'ers have difficulties picking up nonverbal subtleties, and because the child is keeping social contact to a minimum) the learned parent



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is there to help explicitly teach proper modes of interchange. Finally, by providing the compassion and respect which is absent from many other environments in their child(ren)'s life, these parents can reduce the child(ren)'s anxiety levels, which then starves the TS for "fuel" and ironically minimizes the disinhibition and impulse problems which they are displaying understanding for in the first place.

Negative self-worth, which the educated parent has played a vital role in thwarting, can lead to a whole host of problems which could compound and exacerbate the existing TS in your child: research says that children with negative self-worth take on more responsibility for failures in their lives (for example, "I can't stop making these noises because I'm a bad person"), they are unable to discount the importance of success where they are not performing well (for example the child might persist in a futile attempt at making a certain group of peers his/her friends rather than gravitating towards a group of peers who DO like him/her), and they overexaggerate their incompetencies (for example, one poor test mark becomes, "I'm so stupid!! I can't do ANYTHING right!). The picture gets even more grim: poor self-worth then leads to negative affect (anger, resentment, frustration, depression), and low motivation ("Well, since I'm just so stupid there's no point in me even TRYING at school"). No doubt you've seen some of your child in what I've just described. This is no surprise -- TS is brutally obvious to others, frustratingly omnipresent, and difficult to reconcile. Imagine how much worse off (s) he would have been without you.

When I was growing up, my own parents were not familiar with TS. I tried very hard to suppress and/or mask my tics around them, but was still on occasion grilled concerning my "attention-seeking" behaviours, which led me to try that much harder to hide my "secret". I do not harbour any grudges against my parents – I recognize that they did not know better. However, I can assure you all that this obvious parental disapproval was crippling to my self-image: what seemed to them a minor, annoying game to be challenged was in actuality a definitive aspect of who I was, which was being rejected. It led to near-permanent rifts in our relationship which will take many years and many baby-steps to mend fully.

So parental education bolsters parental tolerance of their TS children, which in turn can help maximize the TS child(ren)'s esteem. Parental education in TS can also help one to know how to most efficiently and effectively deal with one's child(ren). You learn that more structure and predictability results in smoother transitions between activities. You begin to realize that Tourettic rages have no intended malice, and that you only increase your own aggravation and your child's mortification by taking them personally. Ways of minimizing stimulation for your TS child (for example, lots of sleep, avoiding "power struggles" when the child is already overloaded, allowing him/her to have a personal, quiet haven) begin to occur to you. You start to discriminate between the concepts of understanding, and permissiveness – while special accommodations for the disorder *should* be made, responsibilities (and consequences for not fulfilling them once those special accommodations have been made) must still exist for the sake of your child's feelings of happiness, worth, and efficacy. You understand that Tourette's only makes a person MORE disinhibited – it doesn't make him/her completely incapable of any and all restraint, just less than average. So rather than treating your child(ren) as an invalid, you treat him/her as near to normal as possible; this grants him/her a dignity and communicates a respect which can eliminate a lot of frustration and feelings of helplessness in that child's life.

Thus far I have commented solely on the influence of education in TS when parents are well-versed. Education



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is twofold however – the TS child him/herself must be involved in the process as well, and the educated parent is integral in this as well. From my experience, it is easy for parents and teachers, once they understand the TS, to forget that the children themselves also desperately need that information. It is true that some children deny their TS: these are the kids of highest need, because in their ignorance they see the diagnosis as an additional burden, when in fact it is the cart with which to carry existing burdens. Some parents may believe that by not talking to the child about the TS, or by denying the impact or severity of the TS, this somehow reduces the blow for the child. I submit that the exact opposite occurs – I believe that children have enough self-awareness to know when something is very wrong or different about the way they act or think. When everyone around that child avoids addressing these concerns, (s)he is robbed of any way of compartmentalizing the bad things that they do, feel, or have happen to them, and they begin to see themselves as simply, and globally, bad. When you educate your child about his/her TS, they are given a way of organizing or “slotting” all of the Tourettic events in their lives. “I’m not running around the classroom because I’m rude, it’s because I have problems with distraction”. “It is not that I’m an ungrateful brat, I trashed my room because I have a harder time holding onto my temper than other kids”. Recognize that I am not advocating using the disorder as a crutch or an excuse here: all I am saying is that to fight one’s enemy, one needs to see it’s face....

For me, education was the vital key to where I am today. It gave me a much needed and sorely missed sense of control in my life – maybe I couldn’t stop the Tourette’s, but I could learn to predict it, and even minimize it through various strategies and coping mechanisms. I was no longer a helpless victim on a runaway train; sure I was still STUCK on the train, but I could use that train to take me places once I knew how it ran. Everyone reacts badly when they are robbed of control: think of the man who loses his temper because he is stuck in an unexpected traffic jam, versus the man who takes an alternative route because he listened to the radio and heard about the delay. Or the anxiety levels of an employee who never knows when he will be called into work, versus the employee on very regular, predictable hours. Or the depression levels of a woman permanently stuck in a bad relationship due to financial need versus a woman who is independently wealthy enough to leave? The only differences between the anger, anxiety, and depression produced in TS, and in these scenarios is in mere degree. Educating the TS children themselves is what GIVES them the information about the traffic jam, or the work schedule, or money to be independent. Some parents with whom I’ve met make the comment that my TS is not “as bad” as that of their child. Realize that this is only because I, through education, now know myself and my TS well enough to develop and implement strategies for avoiding many difficulties, and have found ways of empowering myself despite the TS.

Let me end by again congratulating all of you for what you are doing for your children. It takes ubiquitous strength, and courage to deal with TS, both as a parent and (don’t forget!) as the child. Remember that for each problem you are dealing with now with your child, by becoming educated in TS, and by sharing that knowledge with your child(ren), you have circumnavigated many, many others.

Duncan