

Tourette syndrome: living with the illness and surviving the challenge essay samp...



**ASSIGN
BUSTER**

Introduction

Many children develop temporary minor tics as a normal phase of development. But Tourette syndrome, usually with lifelong symptoms, is the most severe in the range of tic disorders. Despite increasing public and professional awareness, this tormenting disorder is still unfamiliar to many persons, and its bizarre symptoms are easily misunderstood. Admittedly, the muscular tics associated with Tourette syndrome can seem peculiar.

Twitches in the face, neck, shoulders, or limbs may occur. Symptoms may also include odd mannerisms, such as repeatedly touching the nose, rolling the eyes, or pulling or flicking the hair.

Vocal tics can be even more disturbing. Some of these are involuntary throat-clearing, sniffing, barking, whistling, cursing, and repeating words or phrases. “ By the time my daughter was seven,” says Holly, “ she repeated *everything*. If she was watching TV, she would repeat what she heard, or if you talked to her, she would echo what you said. You might think she was being a smart aleck!” What causes these strange tics? Experts say that a chemical imbalance in the brain may be involved. Yet, there is still much to learn about the disorder. Chemical abnormalities are considered important, but *The American Journal of Psychiatry* reports: “ The exact nature of these abnormalities remains to be determined.”

Whatever the exact cause, most experts say that Tourette syndrome is a physical disorder over which the sufferer has little control. Therefore, simply telling a child or an adult with Tourette syndrome, “ Stop doing that” or, “ Stop making that noise,” is futile. “ He wants to stop even more than you

want him to,” says the brochure *Coping With Tourette Syndrome*. Pressuring him to stop will likely add stress, which may even cause the tics to increase! There are more effective ways to cope with Tourette syndrome, for the sufferer as well as for his family and friends.

The Need for Parental Help

Elinor Peretsman of the Tourette Syndrome Association said !: “ Adults who grew up with Tourette syndrome and who are now leading successful lives all say that they got wonderful help from their families. They were loved and supported, not berated or blamed for their condition.” Yes, a child with Tourette syndrome must have— *and must sense that he has* —parental support. For this to be accomplished, parents must work *as a team*. Neither parent should carry the entire load. A child who senses one parent’s passive withdrawal may begin to blame himself for his condition. “ What did *I do* to get this way?” cried one teenage Tourette sufferer. But, as already noted, the tics are involuntary. Both parents can reinforce this truth by taking an active part in the child’s life.

Admittedly, this is not always easy. At times parents—especially fathers—feel somewhat embarrassed by the child’s symptoms. “ I hate to take my boy to movies or sporting events,” confesses one father. “ People turn around and glare at him when he tics. Then I get angry at them, feel helpless about the situation, and end up taking it out on my son.” As this candid statement reveals, often the greatest challenge for parents is their own view of the disorder. Therefore, if your child has Tourette syndrome, ask yourself, ‘ Am I more concerned about the embarrassment that the disorder causes

me than about the embarrassment that it causes *my child?* “ Always put your feelings of awkwardness aside,” urges one parent. Remember, your embarrassment is minute compared with that of the sufferer.

In contrast, mothers usually must guard against the other extreme, that of becoming exclusively focused on the one child to the exclusion of her husband and the other children. Balance is required so that no one is neglected. Parents still need time to themselves. Also, notes a parent named Holly, “ you have to spend private time with each of the siblings, so that they don’t feel encompassed by the child with Tourette syndrome.” Of course, both parents must cooperate to achieve this family balance. What about discipline? Having Tourette syndrome does not take away the need for training. On the contrary, since the disorder is often accompanied by impulsive behavior, structure and guidance are all the more essential. Of course, each child is different. Symptoms vary in type and degree from one person to another. But experts say that regardless of the tics, parents can still teach the difference between acceptable and unacceptable behavior.

Effective Process of Involving Friends and Peers in the Process of Training

Do you have an acquaintance who has Tourette syndrome? If so, you can do much to alleviate his turmoil. How? First, learn to see the person behind the illness. The *Harvard Medical School Health Letter* says: “ Behind the unusual movements, the strange sounds, and the aberrant behavior is someone who desperately wants to be normal and who needs to be understood as a person as well as a patient.” Indeed, persons with Tourette syndrome do feel the pain of being different. This feeling can be more disabling than the tics!

So do not withdraw from someone with this disorder. The Tourette patient needs association. You may well benefit from his company too! Nancy, the mother of a 15-year-old boy with Tourette syndrome, says: “ Those who stay away from my son miss out on the opportunity to learn empathy. We come out of any experience with an education, and living with my son has taught me to be more understanding and not to prejudge.” Yes, insight will help friends to be supportive and not judgmental.

HelpfortheSufferer

Many are relieved simply to know that their tics are due, not to a personal failing, but to a neurological disorder with a name—Tourette syndrome. “ I’d never heard of it before,” says Jim, “ but I was relieved when they put a name to what I had. I thought, ‘ It’s OK. I’m not the only one.’ I’d always felt I was.”

But what can be done about the tics? Many have been helped by medication. However, results vary from one person to another. Some experience side effects, such as muscular rigidity, fatigue, and depression. Shane, a teenager who has tried several medications, says: “ The side effects were less tolerable than the tics. So I decided that I would rather continue without medication as long as possible.” For others, side effects may not be as severe. Thus, whether or not to use medication is a personal decision.

With or without medication, “ the social terrors that must be overcome may be the toughest challenge,” notes *Parade Magazine*. Kevin, a young man with chronic muscular tics, decided to meet this challenge head-on. “ Out of fear of being embarrassed,” he says, “ I used to turn down invitations to play <https://assignbuster.com/tourette-syndrome-living-with-the-illness-and-surviving-the-challenge-essay-sample/>

basketball or to go over to a friend's house. Now I just tell people straight out what I have, and it makes me feel a lot better."

But what if you have Tourette syndrome and your tics are disturbing to others, perhaps including coprolalia, the involuntary outburst of offensive words? You can draw comfort from what the Bible says. It assures us: " God is greater than our hearts and knows all things." (1 John 3: 20) He knows that you would ' put away' this " obscene talk" if you were physically able to. (Colossians 3: 8) Yes, the Creator understands this disorder better than any human. He does not hold one accountable for a physical disorder over which one has no control.

Truths About the Syndrome:

- Tourette syndrome is three times more common in males than in females. For this reason we will refer to the Tourette patient in the masculine gender. Of course, the same principles apply to females with Tourette syndrome.
- Studies have shown that as many as one half of Tourette syndrome patients are also afflicted with obsessive-compulsive symptoms, and one half display Attention Deficit Hyperactivity Disorder symptoms. The relationship between these disorders and Tourette syndrome is still being researched.
- While the link between nutrition and behavioral problems is controversial, some suggest that parents be alert to any foods that seem to intensify a child's tics.

Applying Discipline Even Beyond The Existence of Neurological Disorder

<https://assignbuster.com/tourette-syndrome-living-with-the-illness-and-surviving-the-challenge-essay-sample/>

OBVIOUSLY it would be wrong to chastise a child simply for the involuntary manifestations common to Tourette syndrome. The presence of such behavior does not mean that the child is not being properly disciplined. However, the word “ discipline” can mean “ to train or develop by instruction and exercise.” While tics cannot be eliminated, parents can train the child to subdue unacceptable behavior that is a by-product of the disorder. How?

- TeachhimthatactionshaveA child with Tourette syndrome needs to know that his impulsive actions have consequences. Teach him this by asking questions about everyday matters, such as, ‘ What would happen if this food was not put back in the refrigerator?’ Allow him to respond. He may say: ‘ It would get moldy.’ Then, let him choose a course of action that would prevent the undesired outcome. He may conclude: ‘ We should put it back in the refrigerator.’ If this is done repeatedly and with a variety of situations, the child can be trained to think before impulsively acting.
- SetThis is especially important if a child’s behavior is potentially harmful to himself or to others. For instance, a child with a compulsion to touch a hot stove can be told that he is not allowed near the stove. A child who tends to get excessively angry can be taught to go to a private place until he cools down. Make it clear which actions are appropriate and which ones are not.
- Ifpossible, teachthechildtomodifyobjectionableSome can control their tics temporarily. Often, however, forcing such restraint simply delays the inevitable outburst. A better approach is to help the child modify tics that are socially objectionable. For example, spitting can be made

less objectionable by having the child carry a handkerchief. This teaches the child responsibility for managing this symptom so that he can function in society.

Understandably, Tourette Syndrome is a both physical and learning disability that mostly involve parents in a position of choice, decision and patience.

Likely dealing with this situation should involve the need for one to be more than just comprehensive with the situation but also fully really believing that something could still be done for the improvement of the sufferer.

References:

Itard JMG. “ Mémoire sur quelques fonctions involontaires des appareils de la locomotion, de la préhension et de la voix”. Arch Gen Med. 1825; 8: 385-407. From Newman, Sara. “ Study of several involuntary functions of the apparatus of movement, gripping, and voice” by Jean-Marc Gaspard Itard (1825) History of Psychiatry. 2006 17: 333-39. doi: 10.1177/0957154X06067668.

Scahill L, Erenberg G, Berlin CM Jr, Budman C, Coffey BJ, Jankovic J, Kiessling L, King RA, Kurlan R, Lang A, Mink J, Murphy T, Zinner S, Walkup J; Tourette Syndrome Association Medical Advisory Board: Practice Committee. “ Contemporary assessment and pharmacotherapy of Tourette syndrome”. NeuroRx. 2006 Apr; 3(2): 192-206. PMID 16554257.

Ringman JM, Jankovic J. “ Occurrence of tics in Asperger’s syndrome and autistic disorder”. J Child Neurol. 2000 Jun; 15(6): 394-400. PMID 10868783.