

HELPFUL ARTICLES ABOUT TOURETTE'S SYNDROME

Included in This Packet:

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Educating Classmates about TS
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Understanding Coprolalia
Bullying Prevention: Positive Strategies
Children & Teens with Generalized Anxiety Disorder
Understanding Dysgraphia
Genetics of TS



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FACTS ABOUT TOURETTE SYNDROME

Answers to Most Commonly Asked Questions

What is Tourette Syndrome (TS)?

It is a complex neurological disorder characterized by tics—involuntary, rapid, sudden movements and/or vocal outbursts that occur repeatedly. TS is often accompanied by obsessive-compulsive disorder (OCD), attention-deficit/hyperactivity disorder (ADHD), poor impulse control, and other behavioral issues. TS typically begins in childhood and can vary widely between individuals, with symptoms ranging from mild to disabling. People with TS often find their own symptoms fluctuating in severity and frequency over the course of their lifetime. Tics can sometimes be suppressed for periods of time, but this may cause discomfort and fatigue.

What are the most common symptoms?

Commonly, motor tics may be eye blinking, head jerking, shoulder shrugging, facial grimacing. Vocally—throat clearing, barking noises, sniffing and tongue clicking. Symptoms change periodically in number, frequency, type and severity—even disappearing for weeks or months at a time.

What is ADHD?

Attention-deficit/hyperactivity disorder (ADHD) is characterized by the three primary symptoms of hyperactivity, impulsivity, and inattention. There are three “types” of AD/HD. Some patients with ADHD are predominantly hyperactive and impulsive (e.g. can't sit still, always fidget, interrupt others, blurt things out or make inappropriate comments, difficulty waiting turn). Some patients with ADHD are predominantly inattentive (e.g. make careless mistakes, have difficulty staying focused, difficulty following instructions or finishing things, are reluctant to do things that require mental effort, forgetful, daydream). Some patients with ADHD demonstrate a combination of the two. Despite increased social awareness, these behaviors are often attributed to “lack of motivation”, “not trying hard enough”, or “poor parenting”. If not properly treated, symptoms of ADHD can significantly interfere with a patient's academic/occupational, social, and emotional functioning.

What is OCD?

Simply put, obsessive-compulsive disorder is characterized by the presence of obsessions and/or compulsions. Obsessions are intense, intrusive, repetitive thoughts such as concerns about evenness and neatness, unfounded or irrational fears (e.g. becoming ill, hurting someone/self, causing a flood or other catastrophe), perverse sexual thoughts, excessive concern about a body part, excessive concern with morality, intrusive words, phrases, music, or images. Compulsions are meaningless and/or irrational rituals such as checking, counting, cleaning, washing, touching, smelling, hoarding, and repeating. People with OCD often feel that something terrible will happen if they do not perform their compulsions. These symptoms can cause significant distress and often interfere with a patient's focus, concentration, and efficiency.

What is the cause of the syndrome?

TS is thought to be due to an abnormally functioning basal ganglia, the portion of the brain deep inside the cerebral hemispheres that is most responsible for controlling the body's movement. Some studies suggest that abnormal regulation of the neurotransmitter dopamine reduces the ability of the basal ganglia to inhibit behavior. Unfortunately, the symptoms of many patients are wrongly attributed to “habits”, “allergies”, “asthma”, “dermatitis”, “hyperactivity”, “nervousness” or many other conditions.

Is it inherited?

While the exact cause is unknown, TS appears to be genetically inherited in the majority of individuals. Genetic studies indicate that TS is inherited as a dominant gene, with about 50% chance of passing the gene from parent to child. Sons are three to four times more likely than daughters to exhibit TS.

Is obscene language (coprolalia) a typical symptom of TS?

Definitely not. The fact is that cursing, uttering obscenities, and ethnic slurs are manifested by fewer than 10% of people with TS. Too often, however, the media seize upon this symptom for its sensational effect.

Do outbursts of personal ethnic and other slurs by people with TS reflect their true feelings?

Quite the contrary. The very rare use of ethnic slurs stems from an uncontrollable urge to voice the forbidden even when it is directly opposite to the actual beliefs of the person voicing it.

How is TS diagnosed?

Diagnosis is made by observing symptoms and evaluating the history of their onset. No blood analysis, X-ray or other type of medical test can identify this condition. The TS symptoms usually emerge between 5 and 18 years of age.

How is it treated?

Currently, there is no known cure for TS, but many safe and effective treatments are available to alleviate the symptoms. It is essential that the selection of the therapy is individualized and targeted to the most troublesome symptom. Therefore, a comprehensive evaluation is important, as symptoms associated with ADHD, OCD, or other behavioral difficulties may be more problematic than the tics. Tics usually improve with drugs that block or deplete dopamine or injections with botulinum toxin. Central stimulants, atomoxetine, and drugs that act on the adrenaline system are useful in the treatment of ADHD, impulse control and other behavioral symptoms. Serotonin receptor blocking drugs and other medications are often effective in treating symptoms of OCD. Individuals react differently to the various medications, and frequently it takes some time until the right substance and dosage for each person are achieved. Almost all of the medications prescribed for TS treatment do not have a specific FDA indication for the disorder. In addition, tutoring, counseling, and other interventions may be helpful in addressing academic, emotional, social, and behavioral problems that arise as a result of the impact of TS, OCD, and ADHD on patients' daily lives.

Is there a remission?

Many people with TS get better, not worse, as they mature. In a small minority of cases symptoms remit completely in adulthood.

Do TS children have special educational needs?

As a group, children with TS have a higher incidence of academic or artistic giftedness than the population at large. But problems in dealing with tics, often combined with attention-deficit disorder, obsessive-compulsive disorder and other learning issues may call for special education or 504 assistance. Examples of teaching strategies include: technical help such as tape recorders, alpha smarts or computers to assist reading and writing and access to tutoring in a quiet setting.

How many people are affected?

Between two and three percent of the U.S. population may have TS. In Texas, the estimate is over one-half million people with Tourette's syndrome. TS is 3-4 times more common in males and incidence may be as high as 1 in 100 school age boys and 1 in 300-400 school age girls. All ethnic groups are similarly affected.

What is the prognosis?

In general, people with TS lead productive lives and can anticipate a normal life span. Despite problems of varying severity, many reach high levels of achievement and number in their ranks as surgeons, psychiatrists, teachers, executives and professional musicians and athletes.

What is the Tourette Syndrome Association?

TSA is the only national voluntary health organization dedicated to identifying the cause, finding the cure and controlling the effects of this disorder. Its programs of research, professional and public education and individual and family services are made possible through the generosity of donors. The Tourette Syndrome Association of Texas partners with the national Tourette Syndrome Association. TSA of TX, one of the largest chapters in the country, is a 501(c)3 non-profit organization. We raise private funding to assist area families and children in crisis, 24 hours a day, 365 days a year.

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Generic Academic and Behavioral Accommodations/Modifications

(are appropriate for almost every student with T.S.—either 504 or OHI)

I. Episodic Issues

(Tourette's syndrome waxes and wanes and changes over time with no measure of predictability.)

- A. Practice flexibility with academic and behavioral expectations, especially when symptoms are exacerbated.
- B. Build in late arrival at school when exacerbated symptoms are present – e.g., sleep problems or difficulty with morning tasks.

II. Tics

(Parents – please write a symptom list to present. Update as tics change.)

- A. Increased movement in classroom
- B. Extended time for test taking.
 - 1. Increased difficulty testing due to blinking, hand, shoulder and torso movements
- C. No timed tests
 - 1. Increased anxiety increases tics
- D. Safe place to discharge tics or emotions
 - 1. Pass to Nurse or other previously designated area
- E. Preferential seating – back of classroom close to door

III. Dysgraphia

(Over 90% of all boys with T.S. are dysgraphic)

- A. Decrease all paper and pencil tasks
- B. Provide notes (student must still attempt note taking)
- C. Provide copy of homework assignment
- D. Fill-in-the-blank overheads and worksheets
- E. Use of keyboard/computer whenever possible
- F. Allow dictation: Scribe at home/school if necessary

- G. Shorten assignments without changing content
- H. Extended time to complete assignments
- I. Allow oral responses
- J. Allow voice-activated computer typing programs

IV. ADHD

(Intrinsic disorganization)

- A. Special Homework Plan - *will avoid a string of zeros*
(Mom will need to check binder every day at first)
 - 1. Extra home set of textbooks
 - 2. Parent-generated emails Tuesday and Thursday regarding assignments due and/or missing
 - 3. Extended time (1-2 days) to complete missing assignments without penalty
- B. Short structured breaks
 - 1. Laminated pass for one three-minute break per 20 - 50 minutes
- C. Allow increased movement in classroom
- D. Single instruction or directive

V. Obsessive Compulsive Disorder (OCD)

- A. Allow routines which are not disabling or intrusive, e.g., flipping light switch, sharpening pencil
- B. Provide compensatory strategies/objects for annoying behavior:
 - 1. Soft object on end of pencil for tapping
 - 2. Place in front of line and instruct to keep one arm length between others for compulsive touching
 - 3. "Chewelry" for chewing shirts, pencils or other objects
- C. Assess inattention (intrusive thoughts seriously disrupt learning)
- D. Avoid direct confrontation. Use redirection whenever possible to prevent obsessive-compulsive neuro-rigidity "oppositonality."
- E. Provide transition time. (Allows brain to disengage and engage.)
- F. Provide reassurance for worries, fears or extreme perfection.

VI. Tactile Issues

Hypersensitivity to noise and crowds

- A. Early dismissal from classroom (2-3 minutes)
- B. Use of earphones, earplugs, darkened glasses during designated times

VII. Behavioral Accommodations and Directives for Implementation

Contained classroom is not necessary nor appropriate to implement.

- A. Planned ignoring – tics
 - 1. Tics will worsen if attention is focused on them (increasing anxiety)
 - 2. Pass to Nurse for a short time if tics are overwhelming or disruptive
- B. Use calm, quiet voice for directives and corrections (Child is neurologically over stimulated; quiet voice will help refocus)
- C. Avoid direct confrontation. Use redirection whenever possible to prevent obsessive-compulsive neuro-rigidity “oppositonality.”
- D. Transition time both physically and for directives (Allows brain to engage and disengage from tasks)
- E. Stepwise directives and rules
- F. Provide structure and clear understanding of expectations with flexibility for waxing and waning of symptoms
- G. Provide increased supervision in unstructured settings, i.e., lunch, P.E. and recess
- H. Quiet area to regroup/gain control when over-stimulated
- I. Use positive reinforcement
- J. Do not apply immediate consequences (whenever possible) after escalated behavior has occurred. Wait until child has calmed before disciplining. (Will avoid continued or rapid re-escalation.)

VIII. Education of peers and school staff

The Golden Rule: Avoid academic frustration, utilizing appropriate accommodations and by teaching compensatory strategies.

Goal: Always move the child to the norm.

***** Remember that stress exacerbates all symptoms and behaviors *****

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Generic Academic and Behavioral Accommodations/Modifications

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Problem Behaviors and Tourette Syndrome

by Ruth Dowling Bruun, M.D., Kenneth Rickler, M.D., & Emily Kelman-Bravo, CSW, M.S.

Introduction

Tourette Syndrome (TS) has been defined classically as a disorder of motor and vocal tics. However, in recent years there has been a growing awareness of various other behavioral problems which are sometimes associated with TS. While many people with TS have none of the symptoms discussed here and others may only be mildly affected, this brochure has been written especially for people who must struggle to understand and cope with the associated behavioral problems of TS. Some of these occur with such frequency that they are generally accepted as "associated disorders." Obsessive-compulsive behaviors, attention deficits and hyperactivity as well as impulsive, aggressive and explosive behavioral patterns fall in this category.

Other problems such as self-injurious behaviors, abnormal sleep patterns, phobias, extreme mood swings, depression, and inappropriate sexual behaviors, though less common, have also been identified as "associated disorders" since a number of TS patients have them. Learning disabilities, although not behavioral problems in themselves, may also contribute to the overall adjustment problems faced by a patient with TS.

Which of these problems are integral to TS (caused by the same genetic defect), which may be secondary effects of the biochemical abnormalities responsible for tics and which may be psychologically caused is still a matter of some debate. But, whatever the causes, it is important to understand that people with TS often struggle to cope with the associated disorders on a daily basis and sometimes find them to be far more disabling than the physical tics of Tourette Syndrome.

Before discussing the specifics of the associated disorders it should be made clear that the vast majority of people with TS and other tic disorders are able to lead normal, productive lives. Indeed, many individuals with TS remain undiagnosed because their symptoms are mild and do not require medical attention. On the other hand, the presence of behavioral problems in a child or adult with TS should alert the person, the family and the treating professional to the need for a more thorough evaluation of possible contributing factors. Neuropsychological testing is an important part of such

an assessment and, unfortunately, often is not used. The value of such testing, however, is dependent on the skills of the tester and his/her knowledge of the disorder.

Obsessive-Compulsive Symptoms/Disorder

There is an increasing amount of research evidence that obsessive-compulsive symptoms (OCS), which in their extreme form comprise obsessive-compulsive disorder (OCD), may be an alternative expression of the TS gene. In other words, the gene responsible for TS may show itself by tics alone, by OCS or OCD alone or by both.

Obsessions are defined as recurrent, intrusive, unwanted thoughts which often provoke anxiety. Compulsions are defined as voluntary motor acts which are repetitive, ritualistic and which are performed in order to reduce the anxiety caused by specific obsessions. Even experts may have difficulty distinguishing between a complex motor tic and a compulsion at times. However, this distinction may be important since the medications to which tics most often respond (neuroleptics such as Haldol or Orap) usually have little impact on OC symptoms. Although they may seem very bizarre on occasion, *OC symptoms are not manifestations of psychosis* and there is no higher frequency of psychosis in patients with both TS and OC symptoms than there is among the general population.

Typical examples of compulsions are: the need to "even things up" (e.g. touching an object with one hand necessitates touching it with the other); repetitive, unnecessary counting; checking things over and over (e.g. checking many times to see if the stove is turned off); performing simple actions over and over again (e.g. turning the light switch on and off five times instead of once); excessive cleanliness and/or concern about germs or contamination; and hoarding of useless objects. Sometimes obsessions and compulsions may seem quite bizarre. For example, one young woman with TS and OCD felt compelled to take off her shoes several times every hour to make sure her feet were not bleeding. Although she *knew* that this fear made no sense, she could not stop herself from doing it. Because people with OCD are aware that their behavior is strange they often go to considerable lengths to conceal

it. Thus they are frequently misunderstood (e.g. a student who reads very slowly because of the need to go over certain words repeatedly may be mistaken for a poor reader).

Obsessive-compulsive symptoms may respond to behavior modification therapy which is a type of treatment using conditioning techniques. On occasion, single motor tics may respond to a similar process, but in general, this type of treatment does not benefit patients with tics alone. Measures which reduce anxiety may help to decrease tics in a secondary fashion, but do not seem to have as much impact on OC symptoms. Anafranil (clomipramine), Prozac (fluoxetine), Zoloft (sertraline) and Paxil (paroxetine) are newer antidepressants known as SRI's (serotonin reuptake inhibitors) because their primary effect is to alter brain serotonin levels). Luvox (fluvoxamine), another drug in this same category, is now available in the U.S.

Although they are antidepressants these medications are also effective for the treatment of OCD. If, in very difficult cases, these medications alone are not effective enough, certain other medications may be used to strengthen or bolster them. While these drugs do not seem to have much impact on simple tics, they may be of some benefit for difficulties with impulse control and, of course, for depression.

The spectrum of OC behaviors remains to be clarified. Eating disorders, alcohol and drug abuse, compulsive gambling, compulsive pulling out of one's own hair (trichotillomania), and compulsive sexual behaviors are among the behaviors currently being studied.

Recent research has demonstrated that both behavior therapy and SRI medications have the ability to bring abnormal brain metabolism associated with OCD back to a more normal state. Clinical experience with OCD patients confirms that a combined approach (medication and behavior therapy together) is more effective than either treatment alone.

Attention-Deficit Hyperactivity Disorder

Many studies of TS have shown that the association of attention-deficit hyperactivity disorder (ADHD) with TS is high. It has been estimated that as many as half of all children with TS also have ADHD. Some genetic research has suggested that ADHD and TS are transmitted by the same gene. However, this theory is more controversial than the link between TS and OCD. Simply defined, ADHD is a collection of signs and symptoms which include impairment of the ability to focus and sustain attention as well as difficulty with

various aspects of impulse control. Symptoms typically worsen in situations where sustained concentration is required, i.e., in a classroom or during a business meeting. People with ADHD have trouble sticking with tasks and completing them. They have difficulty organizing and doing careful work. They often give the impression that they are not listening and are forgetful. Impulsivity is demonstrated by constantly interrupting, speaking out of turn, intruding on others' privacy and accident prone behavior. Signs of hyperactivity include the inability to sit still, fidgeting and excessive and loud talking. ADHD children and adults are often stimulus "hungry," and seem to do best in settings offering fast paced change in input and activity. *Structure, consistent limit setting and reduction of distracting stimuli remain the best ways to help in the management of ADHD symptoms.* Although the co-presence of TS adds to the complexity, these principles of management are also valid when TS and ADHD occur together. Difficulties with impulsivity require monitoring and assistance with decision making. *The motto of "stop, think, then act" needs repeated reinforcement.* Some individuals with TS and ADHD may also have difficulties controlling aggressive behaviors with family, peers and authority figures. Since both TS and ADHD involve difficulties with impulse control, it is not surprising that ungoverned impulses are a hallmark of those people with both disorders. This problem is discussed further in the next section.

Making a diagnosis of ADHD may be complicated by the presence of tics which, in themselves, may impair concentration. The presence of learning disabilities can further complicate the picture. *Therefore, a careful analysis of each contributing problem is necessary for the formulation of a plan.* As with emotional factors, neuropsychological testing can be very helpful in clarifying problems.

Drug treatment of TS with ADHD poses special problems and here, as well as with several other aspects of TS, opinion among physicians is divided. Some cases of either TS or chronic tics appear to have their onset shortly after a child is placed on stimulant medication (e.g., Ritalin, Cylert or Dexedrine) which was prescribed for symptoms of ADHD. Although it is acknowledged that stimulant medications may provoke tics, there is no hard evidence that they can cause TS in a person who would otherwise not develop the disorder. Low doses of stimulants may be less likely to cause tics than higher doses. Nevertheless, the conservative approach to treatment has been that of avoiding the prescription of stimulants for any patient with either a personal or a family history of tics. Since neuroleptic medications

such as Haldol (haloperidol) or Orap (pimozide) both of which help to control tics are not usually of much benefit in the treatment of ADHD symptoms, other types of drugs should be considered when ADHD symptoms are severe enough to warrant medical treatment.

Alternatives to the stimulant medications include tricyclic antidepressants such as Tofranil (imipramine) and Norpramin (desipramine). Some of the newer antidepressants such as Wellbutrin (bupropion), Anafranil (clomipramine), Prozac (fluoxetine) and Zoloft (sertraline) may also be helpful. Catapres (clonidine) which has some anti-tic effects has also proven to be useful for treatment of ADHD symptoms, particularly those caused by impulsivity.

Unfortunately, however, none of these medications are usually as effective as stimulants in helping to improve concentration. Therefore, there are times when stimulants may be the treatment of choice for a person with TS providing that these medications are prescribed in a cautious and carefully monitored fashion. In fact, recent data suggest that an increase in tics due to stimulant medication may be mild and temporary. Thus, understandable concern over the possible worsening of TS symptoms due to taking stimulants must be balanced against the potential benefits of those medications for difficult ADHD symptoms. This is both a patient-doctor and family decision which must be made with a thorough assessment of the risks and benefits for each individual's situation. While many people with TS and ADHD first come for treatment because of their tic disorder, it is our observation that ADHD symptoms are sometimes more problematic for them and thus demand the primary consideration.

Although it is often overlooked, attention-deficit disorder without hyperactivity (ADD) exists in both children and adults. It is usually harder to diagnose but deserves attention just as much as ADHD.

It was previously believed that most children with ADHD would outgrow their symptoms. We now know that many adults who may not appear hyperactive still have serious problems with attention and impulse control. Unfortunately, when ADHD or ADD is diagnosed at a later age a person may have suffered considerable loss of self-esteem. Attention problems have in the past been mistaken for lack of intelligence just as impulsivity has been judged to be "bad" behavior.

Merely understanding what is wrong with them may be immensely helpful to adults with attention problems. However, more severely affected persons may need medication and/or behavior therapy to enable them to make a good adjustment and to function up to their capabilities.

Aggressive and Explosive Behaviors

It has already been mentioned that one manifestation of ADHD is the inability to control aggressive impulses. At one time or another everyone will experience the urge to "tell someone off," to scream or cry with frustration, even to punch, kick and throw things. Most of us control these urges most of the time. Some people can control them all of the time. Some, particularly those with TS and ADHD, find it excruciatingly difficult to manage such self control. These people might be described as having a "short fuse." Temper outbursts may be frequent and may rapidly escalate out of control. In more extreme cases, aggressive outbursts may result in physical assaults or damage to property even though the provocation may be relatively minor. Often it seems that once they let their anger out, they cannot rein it in. Typically, these individuals greatly regret their explosive outbursts. Between outbursts they are reasonable and filled with self-reproach.

Management of aggressive, explosive behavior patterns is often difficult. The treatments for ADHD already discussed may be of help. Sometimes OCD appears to be the factor which incites the aggressive behavior. When compulsions cannot be satisfied, feelings of frustration and anxiety may be so intense that a person with little control over their impulses can only resort to exploding with anger.

Other medications which may be helpful for aggressive and explosive behaviors include Tegretol (carbamazepine), Inderal (propranolol), Buspar (buspirone), Desyrel (trazodone) and lithium. Tegretol has occasionally been associated with a mild increase in tics.

Behavior therapy, of some form, is almost essential in such cases. Though it may consist of firm, consistent parenting measures rather than therapy with a professional, children must be taught to manage their frustrations and their reactions to them. In more severe cases, hospitalization or a residential school may be the only viable solution. Unfortunately, there are very few such placements which are appropriate for young patients with Tourette Syndrome. All too often these children are punished for behaviors and symptoms which they genuinely cannot control (such as coprolalia) and, feeling misunderstood, they have little incentive to cooperate with other aspects of any behavioral program.

Self-Injurious Behaviors

Self-injurious behaviors affect a small minority of patients with TS. Hitting or slapping oneself, picking at scabs, violent tics which may tear muscles or injure

joints, and mouth biting are some of the more typical examples. Patients may express the need to persist in these behaviors until a certain degree of pain is experienced. For example, a young boy had to rotate his shoulder in a certain way until he obtained a specific sensation. This unnatural movement resulted in recurrent dislocations of the shoulder.

Should this sort of activity be viewed as a complex tic or as a compulsion? The distinction is hard to make, and in attempting to treat these manifestations, a trial and error treatment approach may be the only solution. Treatment with medications that affect the natural opiate systems (e.g. oxycodone, methadone, naltrexone) have been reported helpful in a very few cases.

Inappropriate Sexual Behaviors

Sexual preoccupations and socially unacceptable behaviors may be more common in young children with TS. Masturbating excessively, touching a mother's breasts, talking constantly about sexual subjects and similar behaviors which are not appropriate for the child's age are most disturbing to parents. However, except in rare instances, inappropriate sexual behaviors are not characteristic of older people with TS. When such behaviors do occur (e.g. exhibitionism or voyeurism), they are usually attributable to a combination of poor impulse control and obsessive-compulsive symptoms. Despite several surveys which indicate that these behaviors occur more in patients with TS than in the general population, it is likely that these individuals also have ADHD, OCD or both. In severe cases, other psychiatric disturbances may be contributing to these problematic behaviors. In any case, a person who violates acceptable standards of behavior must be prepared to take responsibility for his/her actions.

Sleep Disorders

Sleepwalking, increased nighttime waking, bed-wetting, night terrors, and motor and phonic tics which occur during sleep have all been reported as problems for some people with TS. More research is needed on the relationship of TS to sleep disorders. If these problems become severe, it may be wise to consult with a doctor who specializes in sleep disorders. Most large hospital centers have sleep disorder clinics. It should also be noted that the medications used to treat TS and its associated disorders may cause or add to sleep problems.

Mood Disorders, Phobias and Other Anxieties

It is not clear at this time whether mood disorders are associated with TS because of biological factors or are due to the multiple stresses such as innate tensions, social difficulties, parental abuses or rejection. In any case, there appears to be a slightly higher incidence of depression and/or mood instability in TS patients. Since OCD appears to have some biochemical relationship to depression and ADHD to mood swings, having these disorders alone might account for the increased incidence. However, it seems to be common sense that life stresses may contribute significantly to these problems.

Similar factors may account for phobias and other manifestations of anxiety. The effort involved in controlling tics may be far more taxing than it appears to the casual observer. Suppressing tics may be distracting enough to disturb concentration or the effort may cause an increase of tension which, in itself, increases the severity of ticcing. Thus a vicious cycle may be created which leads to a state of chronic anxiety. On the other hand, since phobias and other anxiety disorders are linked to OCD, the underlying connection could be in large part biochemical. Again, neuropsychological testing can be helpful in the diagnosis and treatment of these problems. Hopefully, future research will make this murky area more understandable.

Learning Disabilities

Several studies report an incidence of specific learning disabilities in more than half of people with TS. These problems with learning may be subtle or pronounced. Included in this category are specific types of reading, writing, arithmetic and language problems. Specialized educational testing is highly recommended for a proper diagnosis of such problems as well as for specific treatment recommendations.

Although learning disabilities cannot be considered as "behaviors" they are included here because they may have such a profound influence on a person's life. The child with marked learning disabilities may begin to think that he is stupid or even retarded unless he gets the appropriate help. Without this help, even bright children will get discouraged and may drop out of school.

Other Factors Influencing Behavior

In addition to the considerations already discussed it should be noted that medications used to treat tic symptoms, may give rise to, or contribute to, depression, anxiety, phobic behavior and impaired intellectual

performance—all of which may have a significant impact on school and job performance, as well as social and personal functioning.

Finally, it must be recalled that normal childhood and adolescent behaviors *unrelated to TS* often involve some degree of rebelliousness. When these behavior problems occur in the TS adolescent, it may be confusing and frustrating not only for the youngster but for his/her family who find it difficult to distinguish between behaviors caused by TS and those that are the result of adolescent rebellion or simple misbehavior. When family stress becomes overwhelming, professional help should be considered.

If the picture painted here seems very complex, we must remember that each person with TS is unique, with a wide variety of personal factors coming together to shape that individual's behavior. People with TS and their families often ask which behaviors are "part of TS" and which are not. The answer to this question may be easy for an informed professional or may be impossible for even the most sophisticated and knowledgeable physician. Sometimes only an educated guess is possible.

MANAGEMENT HINTS FOR CHILDREN WITH TS AND BEHAVIOR PROBLEMS

by Emily Kelman-Bravo, CSW, M.S.

Managing children with both TS and the associated problem behaviors described in this booklet can be quite difficult. However, there are parenting techniques that can be helpful especially when tried in conjunction with consultation with *mental health professionals*. We should also bear in mind the significant role medications can play in managing problem behaviors. TS associated behaviors have their basis in physical causes just like motor and vocal tics. Therefore, a child exhibiting the associated behaviors is not a "bad" child, but rather may be exhibiting behaviors which are physical manifestations of TS. However, some problem behaviors can be modified or changed and parents need to analyze which behaviors they want to change. In order to do this they must be able to describe the actual behavior and its frequency, as well as what precedes and follows that behavior.

In this way, parents can begin to formulate consistent rules, expectations and consequences for the undesirable behaviors. While not always easy for children to accept, they still must learn to accept responsibility for their behavior.

General Principles

Consistency

Vital to successful parenting is the ability to be consistent. Some frequent pitfalls occur when we:

1. Make threats we have no intention of carrying out;
2. Respond differently at different times to the same behavior;
3. Give in after taking a firm stand;
4. Don't follow through and check to see if requested tasks have been completed; and,
5. Aren't consistent about enforcing our children's required routines—bedtime, homework, chores, etc.

Moreover, when both parents do not present a 'united front,' children quickly realize that by playing one parent against the other, they can easily thwart the disciplining parent's ability to manage problem behavior. Both parents should always try to be mutually supportive in front of their children. Disagreements between parents should be resolved when children are not present, and serious differences may require the advice and help of a family therapist.

Rules

Rules should be clearly stated and specific. Children should be forewarned about them. For children with attention problems, it is very important to break down your instructions into single steps, and to be sure you have been understood. It sometimes helps to ask your child to tell you what it is that you expect of him or her. Rules should be realistic and used with discretion.

Consequences

Most of us learn that there are different types of consequences for our actions. For example, we are rewarded for positive behavior, and we might be punished or ignored for misbehavior. It is particularly crucial when parenting children with behavior problems to have a well thought out plan with consistent rules and accompanying consequences. When new rules and consequences are laid down, behavior may sometimes worsen at the outset. However, don't become disillusioned, remain patient and give the situation enough time to improve.

Rewards

With most children, rewarding good behavior does make a difference. Too often we only punish—forgetting to say, "That was a good job" or "Thank you for remembering to do that task." Rewards may vary greatly; i.e., monetary, hugs, praise, treats and special attention. If the rewards you offer are not suitable to

your own child's interests and desires, they simply won't work. If, after a while, the child is losing interest, try and be imaginative. Change your rewards over time. When rewards are promised, give them immediately after the desired behavior. Above all, always follow through on your promises. It takes time to change behaviors. Look for small changes in the desired direction, recognize and reward them.

Ignoring

Families sometimes fall into an unproductive pattern of automatically reacting to each others' provocations. Did you ever think of trying to ignore your child's behaviors that are performed solely to 'push your buttons' or to get his or her way no matter what? By ignoring the problem behavior, the child neither gets the reaction he seeks from you nor does he get his own way. In short, the specific behavior no longer works and often will be given up.

Which behaviors should we ignore? Begin by thinking about whether a specific behavior is designed to make you lose your cool or enter into a 'power struggle' to eventually force you to give in—"Yes you will!," "No I won't!" These are the behaviors you might try to ignore. However, we may not want to ignore behavior that involves responsibilities; e.g., not completing homework, chores or habits of personal cleanliness. Behaviors that are highly disruptive or injurious to other people or property should not be ignored; e.g., hitting a brother or sister, destroying household items, playing music loudly when others need to concentrate.

Punishment

Punishment is the most commonly used consequence by parents, but it is not always the most effective means of managing behavior problems. Perhaps a better word for punishment is discipline. One type of discipline that does seem to work is 'time out'—sending the child to a previously designated place (his room, a "thinking chair" or a corner) or removing him/her from an enjoyable activity. The duration, location and the change in behavior required to lift the time out should be clearly spelled out *in advance*. Also, the type of time out should be appropriate to the child's age. Parents may need to repeat the specific time out on several occasions until the behavior is managed. Here again, consistency is the crucial factor—whenever possible, *with each occurrence, the same misbehavior should be met with the same time out location and duration*.

Other types of discipline that can be effective are withholding rewards or a system of fines for

misbehavior; e.g., reduction in weekly allowance or no TV for a specific time period.

TIPS:

1. Discipline should occur immediately following the unacceptable behavior.
2. Give your child a chance to avoid the consequence by providing a warning, "I'm going to count to ten . . ."
3. When discipline is unavoidable, **refrain from personal attacks** such as, "You're stupid, sloppy, lazy, bad." It's sometimes difficult, but try to remain composed. Keep your voice calm.
4. Try to have the consequence '**fit the crime**' when determining its duration. When your child no longer cares about the punishment, it may be time to call it off.
5. Surprisingly, **modest but consistent discipline** makes a greater impression on children than more severe and less frequent discipline.

Specific TS Associated Behaviors

Following are suggestions about management of specific behaviors sometimes associated with TS. However, we should be aware that each individual is unique and may exhibit only one or several of these behaviors. Also, degrees of severity vary greatly. Once again, the importance of *seeking professional help* for your family cannot be over emphasized.

Poor Impulse Control

For those children who consistently *act before they think*, or can't seem to remember consequences from previous experiences, or who generally act recklessly despite apparent dangers, simple explanations of consequences may not be enough. Because these children need more help in remembering cause and effect, parents should spell out in advance what the rules and consequences are for specific unwanted behaviors. Depending on the degree of impulse control impairment, initially, parents may *need to connect* most desirable and undesirable behaviors to positive and negative consequences again and again, until the child begins to think before he/she acts. For example: "If you complete your homework, you can have the treat; if you don't, you'll have to remain in your room."

Defiant, Angry, Aggressive Behaviors

Try not to get 'pulled in' to the child's anger. **Avoid power struggles**. Simply refuse to discuss the matter further until voice levels are down and your child is reasonably in control. If you as parents tend to shout or

use physical punishment, then your children will express their anger similarly. Because children tend to imitate what they see, you may need to reduce their exposure to violent TV shows or aggressive playmates.

With children who are highly aggressive, excessive restrictions may have the opposite effect. Parents may need to help their children learn other ways of solving problems. *Children can be rewarded for non-aggression*; e.g., if you don't fight with your brother over the toys this morning, you can have a special treat. In this way, the child may be motivated to figure out a more acceptable way of handling conflicts.

Try to *address outbursts of anger early on*—in this way, they will not spiral out of control. Expressions of negative feelings can be encouraged, but only in normal, civil tones, e.g., “I will be happy to listen to your complaint when you lower your voice.”

Problems of Attention and Overactivity

Learning is very often affected by problems with attention and overactivity. It is strongly suggested that families *work closely with the school* to: be sure your child is receiving appropriate services and that you receive guidance in helping your child with school assignments.

TIPS:

1. **Cut down on distractions.** Create a quiet, secluded and organized homework area away from TV, games and other people.
2. **Break up tasks** and work assignments into small units and give instructions one at a time. Instead of ‘clean your room,’ which might seem overwhelming to the child, you might first suggest only picking up scattered toys. When that task is completed, then request that clothes be put away. The same principle applies to school work. For example, if an hour of homework has been assigned, help the child break up the work into four, 15 minute segments—or even shorter intervals depending upon the child's individual attention span. If necessary, use a timer and perhaps reward the child. For instance, allot five minutes of homework and then a reward of a brief period of playtime. Once your child has learned to concentrate during the set time, you can then increase the intervals until the maximum amount of concentration time for your child is reached. Coordination with the teacher in determining the length and scope of assignments may be required.
3. Be sure that **instructions are clearly stated** and to the point. Try to convey one idea at a time. You may need to ask your child to repeat what you have just said, and then find out if you have been understood by asking him to explain what you meant.

4. Families will have to learn to live with some overactive behavior. However, you can select those behaviors which are most difficult to endure and develop strategies to make them more tolerable to the whole family. For example, you may find it hard to overlook your child's jumping in the house, but you can put up with squirming at the dinner table. Try and reward the child for each predetermined amount of time that the undesirable behavior does not occur. For example, if your child does not jump in the house for, let's say, three hours, he receives a reward.
5. Outdoor physical activity, and lots of it, can reduce overactivity indoors. Allow for a short period of calming down before entering the home. Once indoors, provide planned activities to help focus the child's energy.

Obsessive, Compulsive and Ritualistic Behaviors

Obsessive compulsive behaviors clearly have their roots in physical causes, and therefore punishing your child will not be productive, and in fact, may be damaging to his self-esteem. *In many instances these symptoms can be reduced with appropriate medications.* Moreover, studies have shown that *behavior modification techniques can be helpful* in reducing symptoms that disturb functioning.

Try to remember that your child does not do these behaviors purposefully, and often feels guilty, embarrassed and frustrated at being unable to control them. You need to identify the nature of the behavior as obsessive-compulsive and convey to your child your understanding of how difficult it must be for him. Remain supportive and non-critical. You may be able to work out strategies to make life a bit more manageable. For instance, if your child can't seem to finish up in the bathroom in the morning due to endless obsessive rituals, try to institute a bathroom schedule for the whole family.

Behavior therapists specializing in treating obsessive compulsive behaviors can offer techniques which may decrease some of your child's more problematic behaviors. For instance, in a series of steps, a behavior therapist may try to supportively encourage a child to decrease the amount of time spent in ritual bed-tapping from eight times to seven. He/she may suggest a timer to get your child out of the shower in 10 minutes instead of 20. The therapist might advise physically removing your child in a supportive way from the compulsive behavior, e.g., away from prolonged staring in the mirror. Behavior therapists sometimes use a technique called ‘thought stopping’ whereby they try to teach clients to ‘catch’ the obsessive thought early on and then distract themselves. “I'm starting to obsess

again about my hair. I'm going to stop right now and think instead about which games I want to play later when my friend comes over."

If you wish to contact the OCD Foundation, please write to: International OCD Foundation, Inc.
18 Tremont Street, Suite 903
Boston, MA 02108
Phone: 617-973-5801

Conclusion

In summary, the techniques covered here may not address all of your child's problem behaviors. It is hoped that they will provide you with some help in managing your child. Once again, it is important to work with a mental health professional who can individualize a plan for managing your child's particular problems. The use of medications, where appropriate, is also critical.

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This publication is intended to provide information about Tourette Syndrome, its management and the medications currently in use. Families should be advised to first consult a physician concerning all treatments and medications.

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TOURETTE SYNDROME ASSOCIATION, INC.

Educating Classmates About Tourette Syndrome (A Peer In-Service)

by Susan Conners, M.Ed., Education Specialist, TSA, Inc.

Introduction

When parents of children with TS or the children themselves are asked about the most difficult part of having TS, the most frequent answer is dealing with peers. Social interactions are potentially very difficult for children with TS. One of the most important things you can do for children with TS is to educate their peers about the disorder. This is admittedly not easy, but it's one of the most successful ways of reducing social problems. Below you will find an outline of a peer in-service training. Obviously, the level of information given will depend on the age of the children who participate in the in-service. Also included is a list of videos and children's books that would be a useful adjunct to the training.

Five Steps to Successful Peer Training

1. Do not begin your in-service by talking immediately about TS. Talk first about other medical conditions that the students might already know about. Begin your in-service by asking questions such as:

- *Does anyone know anything about asthma?*
- *Tell me what you know.*
- *What part of your body does asthma affect?*

- *Does anyone have asthma or know someone with asthma?*
- *Have you ever seen anyone use an inhaler for an asthma attack?*
- *Would you think of making fun of someone that you saw using an inhaler?*
- *What about diabetes?*

Continue with the same questions.

- *What would be bad about having asthma or diabetes?*

2. Now is the time to introduce Tourette Syndrome. If you have the disorder, you can ask students if they have noticed things that you have been doing that seem a little different. If you don't have TS, you could begin by asking if anyone knows any disorders that affect the brain. An example could be someone who has had a head injury from an accident and can no longer walk or someone who has Cerebral Palsy. You can ask questions such as:

- *What does your brain control? (speech, movement, etc.)*
- *Does anyone know a brain disorder that affects movement?*

This discussion will help lead the group to TS. The following explanation of TS may help:

With TS your brain is lacking stop signs. The average person only moves when they want to move. When you have TS, your body

moves when you don't want it to. We call these movements tics. Take time to use the following explanation of what a tic is. A tic is a rapid, involuntary, repetitive movement of any muscular group in your body. A tic can be a shoulder shrug, an eye blink, a facial twitch, an arm or leg jerk, a finger tapping, etc. Try to use examples of tics that the child in question may have.

Talk about vocal tics. A tic could also be a noise that a person makes or a word that is said over and over again. A vocal tic could be a sniffing, a throat clearing, a squeak, a grunt or simply a word or phrase that is repeated.

3. The next area to explore is what causes TS.

We don't really know the cause, but we do know that it's hereditary. With younger children, ask if they know what that means. You can ask questions such as:

- *Name something that you inherited from your parents, e.g. your hair color, etc.*
- *How many of you have ever been told that you look like your mom or dad?*
- *This is called hereditary.*
- *How much control do we have over what we inherit from our parents?*

- *Is it nice to make fun of things we have no control over?*
- *Everybody has something about himself or herself that they are embarrassed about. Some people with freckles hate their freckles. What can you do about freckles? Not much.*

4. The next area to discuss would be the fact that TS is not contagious nor will you die from it. You might then ask the following question:

- *If it's not contagious and you won't die from it, what is so bad about having TS?*

Try to elicit the following three responses:

- a. People make fun of you and imitate you because they don't understand.
- b. Tics can interfere with what you're trying to accomplish. For example, what if you had a tic where you constantly were blinking your eyes. It would make it hard to read, copy things from the blackboard, or watch TV. If you had a finger tic, it would be hard to write.
- c. Tics hurt. Your body is not supposed to constantly move like that. Head jerking tics cause neck pain. Eye blinking tics can cause eye strain and headaches.

5. If the child in question has obvious signs of OCD and/or ADHD, you might also explore these two disorders. Stick with symptoms that are obvious. This is a good place to ask the following questions:

- a. Has anyone ever made fun of you for something you can't help or control? How did that feel? Encourage a discussion of feelings.
- b. Has anyone ever had a sneeze that they were trying to hold in? That's what a tic feels like. You try and try to suppress it but eventually it has to come out.
- c. Does anyone follow baseball? Does anyone know the name of the professional baseball player who has TS? This is a perfect time to talk about Jim Eisenreich, a professional baseball player who has TS. Jim has played for several baseball teams including the Marlins, the Phillies, the Royals, and the Twins. His baseball career almost came to a sudden end when he was 28 years old and was still undiagnosed with TS. TSA, Inc. has a video entitled *Stop It, I Can't* which is great to help children understand TS.

Pamphlets & Videos for Use in Peer Training:

Matthew and the Tics (#A-105)
Simon's Special Sneeze Test (#B-19)
Stop it, I Can't — Video (#AV-3)

For more information, go to <http://tsa-usa.org> publication catalog or call the numbers below.

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Since the mid 1960s medication has been the only real treatment option for children and adults with tic disorders. However, while helpful for many people, its use is often limited by side effects.

In 2001 the Tourette Syndrome Association Behavioral Science Consortium began developing and testing a promising behavioral treatment option. This work has led to the publication of the first large scale study showing that a non-medication treatment can effectively reduce tic severity. This treatment is called the Comprehensive Behavioral Intervention for Tics or CBIT (see-bit).

Although new treatments often bring great excitement and hope, some in the TS community are concerned that promoting behavioral approaches for treating tics may have negative consequences. There is concern that families, co-workers, and teachers will read about CBIT and conclude that tics are willful and easily controlled. We have known for years that this conclusion is incorrect and harmful to people with tics. Expecting people to "stop ticcing" or treating them as if tics are done "on purpose" increases distress and triggers efforts to voluntarily suppress tics, which is ineffective and leads to greater impairment. While there are likely to be people who misunderstand or misuse a powerful tool such as CBIT, we still need to let patients and families of those with TS know about CBIT so that they have choices. The purpose of this brochure is to clarify what CBIT is and isn't, what it can and can't do and how behavioral interventions are helpful in reducing tic severity.

What is CBIT?

CBIT is a non-drug treatment consisting of three important components:

- (a) training the patient to be more aware of tics,
- (b) training patients to do competing behavior when they feel the urge to tic, and
- (c) making changes to day to day activities in ways that can be helpful in reducing tics.

It is important to note that many of these strategies are already commonly used in the management of TS symptoms. Upon hearing a description of CBIT, many adults with TS report that they have come up with similar strategies to manage their tics. CBIT takes the best of these ideas and blends them with strategies that allow people to quickly learn the techniques.

How do you learn CBIT?

CBIT is a highly structured therapy that typically takes place in a therapist's office on a weekly basis. The standard treatment is 8 sessions over 10 weeks, but can be longer or shorter depending on the needs of the patient and his or her family. The first step in CBIT is to teach the patient to become more aware of his or her tics and the urge to tic. Next, the patient is taught to perform a specific behavior that makes the tic more difficult to do, as soon as the tic or urge appears. This "competing response" helps to reduce, and in some cases, even eliminate the tic. For example, a youngster with a frequent throat clearing tic would be taught to engage in slow rhythmic breathing whenever he felt the urge to clear his throat. A competing response chosen for a head-shaking tic might be gently tensing the head or neck muscles. Consistent and repeated practice of a carefully chosen competing response done at the appropriate time is necessary for the treatment to be effective.

The final step of CBIT, the functional intervention (FI), is based on the fact that certain situations or reactions to tics can make them worse than they might otherwise be. The goal of FI is to identify these situations and have the patient and family attempt to change them so the tics aren't made worse unnecessarily. For example, someone whose tics get worse when doing homework or before a presentation at work would be taught to manage their stress before and during these situations.

We've always been told that TS is a neurological disorder and that tics are involuntary. If this is true, then how can CBIT work?

To be very clear, there is absolutely no question that tics are neurological in nature. However, and just as important, tics are often also extremely sensitive to the environment in which they occur. Every person with TS knows that a stressful or hostile environment can make tics worse. Similarly, positive and calming environments can be very helpful in reducing tic severity. In this regard, TS is like diabetes. Diabetes is clearly a medical condition, but is highly influenced by behavioral factors such as consistent diet, exercise, and the ability to monitor blood sugar and take insulin. What CBIT attempts to do is to help children and adults figure out those factors in their environment that make their tics worse; teach these individuals how to create environments that are more stable, predictable and easily manageable; and learn skills to cope with environments that are stressful and tic-challenging.

Since CBIT works, does this mean that people with TS are able to suppress their tics?

Because a person can voluntarily suppress tics for a short period of time, some incorrectly assume that a person with tics should be able to control them all the time. This is not the case. Voluntary tic suppression can be done short term, but is not a very effective strategy for regular use. Voluntary suppression is stressful and people who do it become tired, frustrated and irritable. It is very important to realize that CBIT is **not** the same as voluntary tic suppression. Instead, CBIT teaches people with TS a set of specific skills they can use to manage their tic urges or behaviors, without having to use voluntary suppression. In CBIT we don't want patients to voluntarily suppress. Rather, we want them to practice the competing response that they developed with their therapist. When a person does the right competing response in a calm focused manner, the tic gets better, and they feel better and more in control, not frustrated and irritable. Initially, this requires some effort and concentration, but with practice, both adults and children can learn to do their competing responses and easily participate in routine activities. In this regard, CBIT is like other learned skills which often are effortful in the beginning, but quickly become second nature.

I've been told to ignore my child's tics because making him more aware of tics makes them worse. Won't CBIT make tics worse?

Calling extra attention to tics at home, school or in the workplace makes people more self-conscious about their tics and subsequently tics get worse. The goal of CBIT is not to make children and adults more self-conscious, but rather make them more self-aware of their tics. Our experience with hundreds of TS patients is that as people with TS become more self-aware and understand what TS is, they often relax, feel more empowered and self confident – these emotions are all associated with decreased tics, not increased tics. In CBIT, the goal of self-awareness training is to help people understand their tics and what makes tics better and worse. This self-awareness is often described by patients as beneficial by itself, even without other parts of CBIT.

I've heard that when people with TS try to stop their tics, it will make other tics worse or will cause a rebound in tics after the efforts to stop have ended. Won't CBIT cause these problems, too?

Every clinician who has worked with people with TS has heard a patient say that when they voluntarily suppressed

their tics, they couldn't keep it up and when they stopped suppressing, their tics "exploded." CBIT does not teach voluntary suppression, but rather teaches techniques to control other behaviors that are incompatible with ticcing until the urge to tic or the tic decreases or goes away. Practicing behaviors that are incompatible with ticcing are very different from voluntary suppression. Researchers have conducted studies on these techniques and have shown that strategies used in CBIT do not cause current tics to worsen or new tics to emerge. That's not to say there won't be times when new tics will start or current tics will get worse; that happens in people with TS with or without treatment. However, it isn't the case that either of these things occur as a side effect of CBIT.

Doesn't CBIT simply lead to the competing response becoming a new tic?

When people first hear about CBIT they become concerned that the competing response will become a new tic. There are two parts of a competing response that assure that this doesn't happen. First, we know tics are reduced when people are involved in calm focused activity. So individuals are taught to use the competing response in a calm focused manner for up to one minute or until the urge to tic goes away. Simply focusing on the competing response like this makes it less likely that the tic will occur. Second, practicing the competing response typically leads to a decrease in the tic urge or sensation. As the sensation goes away, the person can stop using the competing response. Once the urge is gone the chance that the competing response will become a new tic is slim.

How effective is CBIT for somebody with TS?

The results from our large, multi-site, National Institutes of Health funded studies show that over half of people who undergo CBIT will have significant reductions in tic severity and improved ability to function. Complete elimination of all tics and other TS symptoms does happen occasionally in CBIT, but it is not what is expected. CBIT is not a 'cure' for TS, rather, CBIT is a tool that when used appropriately can help individuals better manage their tics and reduce the negative influence that tics may have on their lives.

Is CBIT for everybody who has TS or tics?

Although the skills taught in CBIT can be used by everyone with tics, not everyone will necessarily benefit. At this time we don't understand exactly what makes

some people benefit from treatment while others do not. In our clinical experience, teaching this technique to children with untreated ADHD is more difficult because of problems with focusing, impulsivity and low frustration tolerance. Likewise, any other psychiatric or social problem that gets in the way of participating in treatment may make CBIT more difficult. We recommend that before starting CBIT, children and adults get a complete evaluation and address any symptoms that might make it harder for them to learn and practice CBIT. A person can learn CBIT without treating these co-occurring problems, but it might be harder for them and they may not be as successful.

Is CBIT easy to do?

When they first hear about CBIT, professionals, patients and families sometimes say that the treatment seems simple and easy. Make no mistake, time and hard work are needed for CBIT to work well. As with any new skill, CBIT usually requires more work at the beginning to master the techniques and then becomes easier over time.

Should CBIT be used as a first line of treatment, used with medications, or if I use medication can I stop using medication?

It is important to answer this question by first saying that all medication decisions should be made by the patient in consultation with his or her prescriber. Medication is and will likely remain the primary treatment for tic disorders. However, as it becomes more widely available, CBIT may be used increasingly as a first-line treatment, particularly in young children where side-effects and other safety concerns may limit the use of medication. We also know that those who are already taking medication can get additional benefit from CBIT, but we don't know whether someone who learns CBIT will be able to decrease or stop their medication. More studies will be needed to answer this question. It is not recommended to stop tic medications before starting CBIT unless this strategy has been recommended by the patient's prescriber.

Once mastered, will CBIT last a life time?

Our results tell us that most of those who benefit from CBIT will keep their gains. In a recent study, 87% of those who did well in treatment, continued to do well 6 months after treatment. The important thing to remember is that CBIT isn't a cure...it's a management strategy. During CBIT, patients are taught a set of management skills that can be applied for the rest of their lives as needed.

unhelpful, and not what CBIT is all about. That is not to say that teachers, parents, co-workers, and bosses won't have a role in CBIT. In fact, they may play a pivotal role in helping to create and maintain the positive environment necessary for CBIT to be most effective.

Where can I go to have CBIT performed?

CBIT can be taught by a trained psychologist, doctor, nurse, social worker, or other therapist. As with any treatment, the training and skill of the clinician are critical to outcome. It is our recommendation that only therapists who have been trained in the principles of cognitive behavior therapy and have received specific training in CBIT should provide this treatment. Unfortunately, right now, few clinicians have been trained in CBIT.

Now that our collaborative research project has shown how well CBIT can reduce tic severity, we are working closely with the TSA to get the word out to the professional community and to establish training programs in CBIT across the country for professionals who work with TS individuals and their families. Until this is done, there will likely continue to be a shortage of therapists trained in CBIT. Some professionals who are not well-trained in CBIT will try to do the treatment, and it is important to understand that their results may not be as good as the results obtained from a trained and experienced CBIT clinician. We encourage you to select your therapist carefully and ask about their training in CBIT.

Summary

CBIT is a potentially powerful technique that has been demonstrated to reduce tic severity. That a behavioral treatment helps reduce tic severity is a step forward and reflects modern understanding of how the brain can be shaped by the environment. The TSA and the TSA Behavioral Science Consortium is committed to communicating clearly what this research means so the treatment will be used correctly and effectively.

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About the TSA Behavioral Science Consortium

The TSA Behavioral Science Consortium was established in 2001. Members are previous recipients of TSA grant awards who were brought together to enhance progress in this field by testing CBIT. The mission of the Behavior Science Consortium is to develop, test, and disseminate evidence-based behavioral treatments for children and adults with Tourette Syndrome.

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Understanding Coprolalia: A Misunderstood Symptom

by Sue Levi-Pearl & Joanne E. Cohen

Introduction

The purpose of this brochure is to explain coprolalia pronounced cop-row-lahl-ya—one of the most baffling and socially unacceptable symptoms of Tourette Syndrome (TS). TS is an inherited disorder which develops in childhood, and affects people of all races and cultures. Symptoms include motor and vocal tics. Vocal tics are the utterance of noises, words and sometimes unacceptable language. Motor tics involve involuntary movements of the body.

What is Coprolalia?

Coprolalia is the medical term used to describe one of the most puzzling and socially stigmatizing symptoms of Tourette Syndrome—the involuntary outburst of obscene words or socially inappropriate and derogatory remarks. Other examples may include references to genitals, excrement and sexual acts. Although coprolalia is the most widely known symptom of TS, it occurs in only a minority of patients with TS. It is most often expressed as a single word, but may involve complex phrases. There is no way to predict who will develop coprolalia. Copropraxia is a related complex motor tic symptom involving obscene gestures.

For years doctors mistakenly believed that a diagnosis of TS could not be confirmed unless coprolalia was present. Until recently, professionals thought that coprolalia was caused by psychological problems such as extreme frustration, repressed rage or sexuality. It is now understood that the root of this symptom is physical—that is, neurobiological in nature. While little research has focused on understanding coprolalia, data now indicate that fewer than one third of all people with TS exhibit this symptom at some time during their lives.

However, for those with coprolalia who are trying to deal with the world—in public places, school, at home or work—just getting through the day can be excruciatingly difficult.

How is Coprolalia Manifested?

While obscenities and profanities may be common in everyday conversation in our culture, coprolalia is different from simply swearing or using bad language. Usually these vocal tics are not uttered within social or emotional contexts, and often are spoken or repeated compulsively in a louder tone or different cadence or pitch than normal conversational speech. Particularly embarrassing for some individuals with coprolalia are involuntary outbursts *within* social contexts, such as racial or ethnic slurs in the company of the very people who would be most offended by such remarks. A minority of people with coprolalia have this particular problem.

It is crucial to understand that these words or complex phrases do not necessarily reflect the thoughts, beliefs or opinions of the person with coprolalia. Some phrases can be quite complex, often meaningless and even comical. One young man with TS has been known to shout, "Help me, my underwear is on fire!!"

Some people with TS do not actually say the inappropriate words out loud, but may repeat them mentally. Although not socially apparent, these individuals find their subvocalized coprolalia distressing. The words are usually expressed in a person's native language, but it is not uncommon for someone with TS to swear in a language he or she has learned.

What Causes Coprolalia?

The most commonly accepted explanation of what causes coprolalia involves the same "faulty wiring" of the inhibitory mechanism of the brain that causes involuntary movements that typify TS. It seems that the innate ability we all have to suppress unwanted movements and unconscious thoughts is somehow impaired in people with TS. Just as people with TS must satisfy the overwhelming urge to twitch, so they must "let out" sounds and words that build up and must be expressed before momentary relief can be felt. Depending on the

Understanding Coprolalia

symptom severity, the pressure to express those symptoms will reoccur, because the irresistible, unbearable urge to twitch, curse or shout cannot be inhibited indefinitely. The particular choice of such language may have to do with the individual's stronger emotional content in certain parts of the brain. Such symptoms have been seen in individuals following stroke or other brain injury to the deep frontal regions of the brain. As with all tics, increased symptoms may occur with heightened emotional stress, pleasant excitement or even fatigue. The emotional state does not *cause* the tic symptoms, but rather may increase them.

How Do People Cope?

Some people with coprolalia have discovered ingenious ways to hide or mask their outbursts when they are in social or work situations. They might utter only the first letters of a four letter word, (e.g. "ff" or "shhh"). Others may quietly mumble the unacceptable words or cover their mouths to muffle the obscenities. These masking techniques help to relieve the irrepressible urge to let out the involuntary symptoms, while at the same time mute the unacceptable and disruptive outbursts.

Often the ability to substitute the obscenity with another word is limited, because a major change in the

sound leaves the underlying urge unsatisfied. One way to understand this is to imagine that one has a cold, but that it is socially unacceptable to sneeze in public. It may be possible to cough instead of sneeze, but the urge to sneeze persists, and eventually we just have to sneeze.

Children may also have coprolalia. Because they are less socially sophisticated, youngsters may not try or even be able to mask or hide their outbursts. Severely affected adults with continual vocal tics may not be able to suppress or mask these symptoms. Unfortunately, some have no warning when coprolalia is about to occur.

Summary

Coprolalia is surely among the most difficult symptoms that a minority of individuals with TS must endure. The public often views these behaviors as either strange or offensive and hostile. However, the presence of coprolalia symptoms is not related to one's intelligence or character. Somehow, there are people with coprolalia who develop an exceptional ability to cope with TS and its ramifications. Understanding and acceptance of the symptoms of Tourette Syndrome is a key element in helping people with TS lead full and productive lives.

THE AUTHORS

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ADDITIONAL TSA RESOURCES

Videos & Vignettes

AV-9 After the Diagnosis . . . The Next Steps

Produced expressly for individuals and families who have received a new diagnosis of TS. This video was developed to help clarify what TS is, to offer encouragement, and to dispel misperceptions about having TS. Features several families in excerpts from the Family Life With TS A Six-Part Series who recount their own experiences as well as comments from medical experts. Narrated by Academy Award Winner Richard Dreyfuss. 35 min.

AV-10 The Complexities of TS Treatment: A Physicians' Roundtable

Three internationally recognized TS experts, Drs. Cathy Budman, Joseph Jankovic and John Walkup provide colleagues with valuable information about the complexities of treating and advising families with TS. Emphasis is on different clinical approaches to patients with a broad range of symptom severity. Co-morbid and associated conditions are covered. 15 min.

AV-10a Clinical Counseling: Towards an Understanding of Tourette Syndrome

Targeted to counselors, social workers, educators, psychologists and families, this video features expert physicians, allied professionals and several families summarizing key issues that can arise when counseling families with TS. Includes valuable insights from the vantage point of those who have TS and those who seek to help them. 15 min.

**AV-11 Family Life With Tourette Syndrome . . . Personal Stories . . .
A Six-Part Series**

Adults, teenagers, children, and their families . . . all affected by Tourette Syndrome describe lives filled with triumphs and setbacks . . . struggle and growth. Informative and inspirational, these stories present universal issues and resonate with a sense of hope, possibility, and love. 58 min.

An up-to-date Catalog of Publications
and Videos can be obtained by contacting:



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Bullying Prevention: Positive Strategies

I. Use Positive Strategies to Protect Your Child with a Disability from Bullying

By Julie Holmquist, PACER Center
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Jane has Tourette Syndrome and delayed social skills. Taking advantage of this, a group of popular girls invited her to join them on "clash day," when they said they would all wear outlandish clothes. Jane was excited about being included in the popular group, but on "clash day," she was the only one to dress in this manner. The stares, laughter, and name calling from classmates humiliated her. School staff thought Jane was deliberately disrupting classes and suspended her for the day. She was too embarrassed and hurt to explain. After this experience, Jane never raised her hand in class, did not attend extracurricular activities, and her grades plummeted.

While any child can be a target of bullying, children with disabilities and conditions such as Tourette Syndrome like Jane can be especially vulnerable. Research concerning children with disabilities and bullying indicates an increased risk for children with special needs. According to the AbilityPath.org report, "Walk A Mile In Their Shoes: Bullying and the Child with Special Needs," the statistics are wide ranging:

- A 2008 study in the British Journal of Learning Support found that 60 percent of students with disabilities reported being bullied compared to 25 percent of the general student population;
- In 2009, researchers Wall, Wheaton and Zuver reported that only 10 studies have been conducted in the United States on bullying and developmental disabilities, yet all the studies found that children with disabilities were two to three times more likely to be victims of bullying than their non-disabled peers;
- A survey of nearly 400 parents of children with autism conducted by Massachusetts Advocates for Children in 2009 found that 88 percent of children with autism have been bullied at school.

PACER Center, a National Parent Center serving families of children with disabilities, noted in early 2000 that calls from parents of children with disabilities about bullying situations were increasing. One parent of a boy with cognitive disabilities told Paula Goldberg, PACER's Executive Director, about how several teenage boys were slamming his son's head into the school lockers on a daily basis. Because of these alarming reports, PACER took action and began developing bullying prevention resources.

PACER created its National Bullying Prevention Center in 2006, which offers free resources for all children and others through three websites: PACERKidsAgainstBullying.org (for elementary-age children), PACERTeensAgainstBullying.org (for middle and high school students), and PACER.org/Bullying (for schools, parents, and communities).

PACER also founded National Bullying Prevention Month in October, which raises awareness about how bullying affects children. Like other children, a child with disabilities who is bullied may grow

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angry, resentful, frightened, or apathetic at school, and is at risk for low self-esteem, school avoidance, depression, lower grades, and increased violence.

Parents can help protect their children with disabilities from bullying and its devastating effects if they promote effective strategies such as PACER's Peer Advocacy Program, use the Individualized Education Plan (IEP) as a tool, work with the school, and know their child's rights under the law.

Promote Peer Advocacy

Before Julie Hertzog became the director of PACER's National Bullying Prevention Center, she was a concerned parent. Because her son, David, was born with Down syndrome, was nonverbal, had a Pacemaker and a feeding tube, she was worried that he would be vulnerable to bullying. As she advocated for her son with school staff, she realized how much student interaction happens outside the view of adults, and that David's classmates could be powerful allies for her son in bullying situations.

When David was in sixth grade, Hertzog worked with the school to create a unique support for him. A group of his classmates received training on how to prevent bullying and speak out on David's behalf. They called these students peer advocates. If they see bullying, they intervene, ask the bully to stop, or report the situation to an adult.

The idea worked for David. Now, what started as four kids in sixth grade has evolved into a school-wide project with more than 40 students volunteering to become peer advocates so they can help David as well as other students who have differences. It's a strategy that any parent can explore and discuss with their child's school staff.

To be sure, not all children with Tourette Syndrome will need this level of peer support. Some will welcome a degree of assistance in educating peers and teachers about Tourette Syndrome. There are children who will not be comfortable with intervention or not be ready. Others may be more inclined to self-advocate. Nonetheless, the idea of developing a school environment that promotes peer leadership and intervention, especially when peer advocates see kids being bullied, can be very effective.

"Peer advocacy—students speaking out on the behalf of others—is a unique approach that empowers students to protect those targeted by bullying," says Hertzog.

It works for two reasons: Students are more likely than adults to see what is happening with their peers, and peer influence is powerful. In fact, research shows that more than 55 percent of bullying situations stop when a peer intervenes.

For more information about the peer advocacy program or how to start one at your child's school, visit PACER.org/bullying/resources/peer-advocacy.asp.

Use the IEP

Students with disabilities who are eligible for special education under the Individuals with Disabilities Education Act (IDEA) will have an Individualized Education Program (IEP). The IEP can be a helpful tool in a bullying prevention plan. Remember, every child receiving special education is entitled to a free, appropriate public education (FAPE), and bullying can sometimes become an obstacle to receiving that education.

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The IEP team, which includes the parent, can identify strategies that can be written into the IEP to help stop the bullying. It may be helpful to involve the child, when appropriate, in the decision-making process. Such strategies include:

- Identifying an adult in the school whom the child can report to or go to for assistance
- Determining how school staff will document and report incidents
- Allowing the child to leave class early to avoid hallway incidents
- Holding separate in-services for school staff and classroom peers to help them understand a child's disability
- Educating peers about school district policies on bullying behavior
- Reassurance from the school staff to the student that he or she has a "right to be safe" and that the bullying is not his or her fault
- Shadowing by school staff of the student who has been bullied. Shadowing could be done in hallways, classrooms, and playgrounds.

Work with the School

It's important for parents to believe their child if he or she tells them about a bullying situation. Parents should communicate support to their child, explain that being bullied is not his or her fault, and that no one deserves to be treated this way.

Once parents have reassured their child in this way, they can meet with the principal and share what they know, explain how the situation is affecting their child, and ask the principal what the school can do to keep their child safe at school and on the bus. It's also a good idea to ask if the school has a written policy on bullying and harassment. If it does, request a written copy. Keep a written record of what happened at this meeting, including names and dates.

If a bullying situation is not resolved after meeting with the principal, parents should send a brief, factual letter or e-mail to the district superintendent requesting a meeting to discuss the situation. Copies of this letter can also be sent to the principal, special education director, and chair of the school board. Parents should make sure to keep a copy. A sample letter pertaining to children with disabilities is available at PACER.org/bullying.

Families may also wish to contact a parent center or advocacy organization for assistance. To find a local one, visit ParentCenterNetwork.org or call 888-248-0822. Many TSA chapters offer education, resources and other supports. TSA Chapter information may be found at www.tsa-usa.org or by calling 718-224-2999 Ext. 232.

"Remember, you are your child's best advocate," says Julie Hertzog, Director of PACER's National Bullying Prevention Center. "If your child does not feel safe, you may decide to change schools. Your child's safety and well-being are of the utmost importance."

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Know the Law

If bullying is based on your child's disability, it may violate your child's federal legal rights under Section 504 of the Rehabilitation Act of 1973, Title II of the Americans with Disabilities Act, and the Individuals with Disabilities Education Act.

In a Letter to Colleagues issued on October 26, 2010, the U.S. Department of Education's Office of Civil Rights (OCR) informed all U.S. public schools that bullying and harassment, including harassment of one student by another, can be a form of prohibited discrimination. Federal law prohibits discrimination, including harassment, in education programs and activities, on the basis of race, color, national origin, sex, gender or disability. Find the OCR letter at PACER.org/link/ocr-letter-oct-2010.asp.

According to the OCR and Department of Justice, however, not all bullying constitutes "harassment," and the specific conduct must be examined to determine if civil rights were violated.

Defining Disability "Harassment"

In 2000, a Dear Colleague letter issued by the OCR and Office of Special Education and Rehabilitative Services (OSERS) defined the term "disability harassment." Find it at: PACER.org/link/ocr-letter-july-2010.asp.

"Disability harassment under Section 504 and Title II is intimidation or abusive behavior toward a student based on disability that creates a hostile environment by interfering with or denying a student's participation in or receipt of benefits, services, or opportunities in the institution's program. Harassing conduct may take many forms, including verbal acts and name-calling, as well as nonverbal behavior, such as graphic and written statements, or conduct that is physically threatening, harmful, or humiliating.

When harassing conduct is sufficiently severe, persistent, or pervasive that it creates a hostile environment, it can violate a student's rights under the Section 504 and Title II regulations. A hostile environment may exist even if there are no tangible effects on the student where the harassment is serious enough to adversely affect the student's ability to participate in or benefit from the educational program. Examples of harassment that could create a hostile environment follow.

- *Several students continually remark out loud to other students during class that a student with dyslexia is 'retarded' or 'deaf and dumb' and does not belong in the class; as a result, the harassed student has difficulty doing work in class and her grades decline.*
- *A student repeatedly places classroom furniture or other objects in the path of classmates who use wheelchairs, impeding the classmates' ability to enter the classroom.*
- *A teacher subjects a student to inappropriate physical restraint because of conduct related to his disability, with the result that the student tries to avoid school through increased absences."*

Parents can file a civil rights complaint with the OCR. For instructions on how to file OCR complaints, see <http://www2.ed.gov/about/offices/list/ocr/docs/howto.html>.

Bullying Prevention: Positive Strategies

Although children with disabilities face a higher risk of being bullied, parents can take proactive steps to ensure their child's safety. Promoting innovative ideas such as PACER's Peer Advocacy Program, using the IEP as a bullying prevention tool, working with the school, and knowing the law can help parents protect children with disabilities from bullying. Learn more at PACER.org/bullying.

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II. Suggestions for Parents

Educating students about Tourette Syndrome can be an effective way to prevent bullying. When students understand what TS is, they generally become more comfortable with their classmate and are less likely to condone the bullying. These suggestions offered by the TSA and the National Bullying Prevention Center can guide parents and their children in educating others about TS.

In Elementary School

Parents may want to connect with the teacher before the start of the school year and discuss TS awareness education for the teacher, other school staff, and the child's classmates. At this age, children look to adults to set the rules, so a teacher can help establish essential boundaries regarding acceptance and respect as well as opportunities to create powerful allies and supports for the student with TS.

Parents should make sure the teacher understands the specific impact of TS on their child and enlist the help of the teacher or a social worker to promote awareness in the classroom. For a seven year old, parents can take the lead and the child can participate as a helper. Age-appropriate visual aids can be helpful in classroom presentations — pictures, illustrations, or a short video are all good ideas. Another option is to ask an older child (a sibling, another child with TS, or a member of the TSA Youth Ambassadors) to address the class with a simple and understandable message.

In Middle School

Once students are in middle school, peer-to-peer interactions begin to take priority in their lives, and this requires new bullying prevention strategies. While parents should make sure teachers and school staff understand the disability, they should also help their child take the lead in educating classmates about TS. In this way, students can gain the respect of peers. A student who is already aware of TS might be enlisted to help educate other classmates, or the subject could become part of a class-wide discussion of what makes each student unique. Such a discussion would naturally open the door for students with TS to talk about their own experience with TS.

M, a teen with TS and member of the TSA Youth Ambassadors, discovered that connecting with the bystanders and turning them into allies was much more effective than confronting — or even educating — the bullies. He and his mother invited classmates who had been bystanders to the bullying to go bowling. These students were able to get to know M as a kid with a great sense of

Bullying Prevention: Positive Strategies

humor and a cool mom, and not only as a boy with TS. The kids couldn't stop talking about the fun they had bowling, and when the bullying began again, the bystanders defended M. Some of the bullies gradually "switched sides" and now join them all for Friday night bowling.

In High School

In the teen years, the development of self-advocacy skills is critical. Students with TS should take the lead in deciding how best to educate classmates about TS and how to tell their personal story.

M, a teenager and member of the TSA Youth Ambassadors, warns that when a teen decides to educate his class about TS he should keep in mind the nature of the information he shares — and the interests, maturity level and motivations of his audience. In M's case, talking about his echolalia backfired, as insensitive kids used it to provoke him to mimic inappropriate sounds. It is important to balance the curiosity of the other students with what they need to know in order to accept the classmate who is different. In this case, revealing a tic trigger was too much information for the group.

J, a teen with TS who recently became a TSA Youth Ambassador, had a more positive experience. He made a point of educating his track teammates as well as classmates. At a track meet he was ficking while the officials went over the meet's rules. He was told by uninformed meet referees to 'shut up,' and his teammates immediately defended him, informing the officials that he had TS. Once educated about TS, J says his friends have stood up for him on many occasions.

Thank you to Julie Holmquist and Julie Hertzog at PACER for generously sharing invaluable information with TSA and the TSA audience. Thanks also to Kathy Giordano, TSA Education Specialist, and Candy Korman, TSA Staff Writer, for their contributions to this project.

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Children and Teens with Generalized Anxiety Disorder

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Defining the Problem

We all experience anxiety at some time during our lives; it is normal and even healthy, since it fosters alertness and motivates us to take action. For some people, however, anxiety over everyday activities and events becomes a constant and pervasive condition that impedes their ability to live full lives. The American Psychiatric Association *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition*, describes persons with anxiety disorders as those who experience intense worry, fear, or uneasiness to a degree that interferes with their everyday

functioning over a long period of time. The category of anxiety disorders comprises several different types of disorders, including generalized anxiety disorder, separation anxiety, social phobia, obsessive-compulsive disorder, panic disorder, and posttraumatic stress disorder. This chart will specifically cover generalized anxiety disorder, or GAD.

Typically, children or adolescents who have GAD will experience excessive worry and fear about a number of concerns for a period of at least six months, along with an inability to control the worry. Some of these concerns may relate to real life (e.g., school, social activities, events in the outside world), and some may be unlikely or unrealistic (e.g., being hit by a meteor). This free-floating worry may not be linked to a specific aspect of life; children may simply feel anxious all the time for no apparent reason. The constant worrying impairs children's ability to function in day-to-day life and causes them to need constant reassurance and support from those around them. Such children are often perfectionists, dissatisfied even when their work is perfectly satisfactory to the outside observer. They will also display at least one of these symptoms: feeling restless or tense; becoming tired easily; having difficulty sleeping; having trouble concentrating; being irritable; or feeling muscle tension.

(continued on p. 2)

Goals in Developing a Treatment Plan

- To help children to recognize when they are feeling anxious and to examine their own feelings
- To encourage children to see fallacies in their thinking and consider evidence that contradicts their worst fears
- To help children develop effective problem-solving skills so that they feel more in control of their lives
- To help children develop stress-management skills, including a repertoire of behaviors (e.g., deep breathing) to help them cope with the symptoms of anxiety and avoid or reduce environmental stressors that trigger anxiety



About Instant Help Charts

This chart is intended to provide a summary of the critical information available on helping children and teens with Generalized Anxiety Disorder to insure that every child gets appropriate and comprehensive consideration.

Assessing GAD

Assessment of the child with an anxiety disorder requires at least these steps:

- An interview with the child and a determination of the appropriate diagnosis according to DSM-IV criteria
- A full evaluation of the child's functioning at home through interviews with the parents and direct observation of the child's interaction with them
- An evaluation of how the child functions at school, through interviews with teachers and perhaps guidance personnel and a review of school reports and records

Among the topics to be considered in the assessment are:

- A description of the child's problems and symptoms
- The child's developmental history, current social relationships, and school functioning
- The child's medical history, both physical and psychiatric
- Parents' medical and psychiatric histories

As part of the evaluation, the therapist may administer one or more standardized anxiety scales, such as the *Multidimensional Anxiety Scale for Children* (MHS, Inc., 1997), the *Revised Children's Manifest Anxiety Scale* (Western Psychological Services, 1985), or the *State-Trait Anxiety Inventory for Children* (Consulting Psychologists Press, 1973).

Counseling Children and Teens with GAD

Several forms of therapies appear to help children who have GAD. Simple supportive therapy may be enough to help those with mild anxiety feel better. Clinicians frequently use cognitive therapy to help children learn to view problems more realistically and gain a better perspective on them by correcting the misconceptions and exaggerated worry that characterize the child with GAD. The most commonly prescribed treatment is cognitive therapy combined with behavior therapy, which encourages the child to learn new behaviors by practicing them in small,

(continued on p. 2)

Defining the Problem *(continued)*

There are varied theories about the causes of anxiety. Many practitioners believe that a combination of biological and genetic factors, family practices, and environmental causes interact to produce GAD. It is likely that people with GAD have a genetic predisposition to the disorder; GAD tends to run in families, although this pattern could also be the result of learned behavior. There is evidence that an imbalance in two specific brain chemicals plays a role in the development of anxiety. Other researchers note that observing family members react strongly to occurrences such as thunderstorms may teach the child to be fearful; exposure to stressful life events (losing a parent; seeing on television the terrorist attacks in New York and Washington, D.C.) may also foster a sense of anxiety. General personality traits, such as shyness or excessive fear of unfamiliar places or situations, may make a child more likely to develop GAD.

Counseling Children and Teens with GAD *(continued)*

incremental steps; the combined treatment is known as cognitive-behavioral therapy (CBT). Both cognitive and cognitive-behavioral treatment are usually time-limited therapies that seek to ameliorate symptoms by modifying thought processes and behaviors. Deep-muscle relaxation techniques, self-hypnosis, and biofeedback to reduce the physical symptoms of anxiety, such as palpitations and muscle tightness, can also help.

Active parent involvement is important in helping children with GAD. This can include family therapy aimed at discovering what parents may be inadvertently doing that reinforces the child's anxiety and looking for intrafamily behavior patterns that the child is copying; or it may support the parents as they deal with their child's problem and give them techniques for helping their child cope better. Various organizations offer support groups that enable parents to exchange experiences and ideas.

Fast Facts

- In children, GAD most often occurs in mid-childhood and among teens. It frequently occurs in conjunction with mood disorders, especially depression, and with other anxiety disorders, such as obsessive-compulsive disorder.
- Certain fears and anxieties that typically develop in children at specific ages are normal and will probably resolve themselves. For example, children ages 4–6 often are afraid of monsters and ghosts; somewhat older children, ages 6–9, worry more about school achievement and social acceptance. Teens often worry about whether they will fit in socially, whether they will have friends, and whether they will succeed academically. A child who has such fears is showing developmentally normal behavior that does not indicate an anxiety disorder.
- For the diagnosis to be GAD, the child must experience intense, generalized anxiety so severe that it interferes significantly with everyday functioning; there may also be physical signs of anxiety, such as palpitations or headaches.

What Teachers Need to Know

- Refusal to go to school is a common symptom among children with GAD. They may develop physical symptoms, such as stomachaches, as a way to avoid a setting that they perceive as anxiety-producing. Once in school, they may display a range of behaviors that teachers need to be alert to.
- Although the common perception is that children with GAD are quiet and conforming, some children try to deal with their feelings by being disruptive and demanding attention. Such behavior is disturbing and frustrating to both teachers and parents, who may not understand that it is an attempt to deal with upsetting feelings. Anxious children who act out in this way usually feel very guilty about it and need quiet reassurance that they are still valued by the important adults in their lives.
- Children with GAD often use avoidance behaviors, such as procrastination, to try to deal with their feelings. They may also seem distracted or inattentive. Teachers can be helpful by checking in with students periodically to ensure that they are keeping up with assignments. Setting intermediate deadlines that break large assignments into more manageable pieces can also help.
- While excusing a child with GAD from classroom responsibilities is counterproductive, a bit of flexibility in imposing demands can help the child who is feeling overwhelmed.
- Teachers should communicate their concerns about a child's school performance to both parents and the school counselor; teachers and parents should be in agreement as to how they intend to structure work assignments and modify the student's workload to reduce anxiety. For example, parents can check whether the student is meeting assignment deadlines, completing homework, and so on. Teachers can also help parents modify any unrealistic expectations they may have for their child's performance.
- Children with GAD do better in structured settings where they know what to expect; they consequently do better in classroom settings that are predictable and consistent. If there is to be a major change in the classroom routine, teachers can help by alerting the student and discreetly discussing the change in advance.
- Teachers should avoid singling out anxious students, whether to lead a group activity, perform work at the board, or be made conspicuous in other ways. Students with GAD usually prefer not to be the focus of attention.



The Dos and Don'ts of Communicating

DON'T

- Belittle children's concerns or make fun of them. To the children, they're real and not at all funny.
- Set unrealistic expectations for children's behavior or achievements.
- Compare children with others or point out their shortcomings.
- Focus on children's anxiety so much that you fail to encourage and support normal, everyday activities.
- Reinforce the idea that there is something to be afraid of by giving in to children's fears. For example, don't go out of your way to avoid a dog that the child is afraid of; instead, offer a few gentle words of support as you approach the animal.
- Tell children to relax or be calm. They would if they could.

DO

- Talk to children about their feelings. Getting their emotions out in the open can help children feel more in control.
- Encourage children to learn to think positively and to counter persistent negative thoughts with more hopeful thoughts.
- Help children break down overwhelmingly large tasks into smaller, more achievable ones.
- Point out facts that contradict or offer alternative explanations for things that children worry about.
- Encourage children to accept less than perfect performances in school and at home.
- Teach children to repeat positive, self-encouraging statements to themselves (e.g., "I can do this.") to counter their fear.

What Parents Need to Know

- Parents should not ridicule their child's fears; the concerns are realistic to the child who feels them.
- Parents should make an effort to understand their child's disorder. They can do this by reading books or visiting Web sites, talking to their child's doctor, or attending information sessions and support groups. Names and addresses of support groups are available from the Anxiety Disorders Association of America (<http://www.adaa.org/GettingHelp/SupportGroups.asp>) and many other sources.
- GAD often first appears in children around age six or seven, as they begin school. Children who worry excessively about their school performance around this time may be also at risk for developing GAD later on.
- Parents can reassure their children that they are doing everything possible to keep them safe. If difficulties at home are contributing to children's anxiety, parents can talk to them, quietly and openly, about the situation.
- Parents can use role-playing to help prepare children for situations they will face; sometimes it helps for children to draw pictures of their fears or to write about them.
- Encouragement and recognition for even small achievements and an understanding that anxiety will increase during stressful times, such as periods of transition (a family move, a new school), can help.
- Parents should be aware that children often say they are afraid of particular things to avoid having to name the real sources of their fear.
- Parents might consider whether their children, especially younger children, would be better off without violent or frightening television shows or video games. Children cannot always distinguish reality from fiction and may fear that they too will be victims of an attack.
- GAD is often accompanied by sleep disturbances. Parents can help alleviate this problem by curbing children's intake of caffeine, which is found not only in coffee but in cola drinks, some cold medications, and some diet pills as well. Children often find structure reassuring, so setting up a routine for them to follow every day can also help them sleep better.
- Parents should be aware that teens sometimes abuse drugs or alcohol as a way to self-medicate against pervasive anxiety. If parents suspect this behavior, it is imperative that they get professional help for their teen.



Instant Help for Children and Teens with Generalized Anxiety Disorder

This Instant Help Chart was written by
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Medication Protocol

There is some controversy about when and whether to begin medication with anxious children. Some therapists prefer to try a form of psychotherapy first and move to medication if that does not reduce the child's symptoms sufficiently. Others believe that it is preferable to begin with medication to reduce anxiety so that the child can participate in and derive the maximum benefit from psychotherapy. In any case, before medication is prescribed, the therapist should arrive at a diagnosis through a full evaluation of the child's functioning, perhaps including use of one of the available anxiety scales; evaluate the severity of the symptoms; and discuss the treatment plan with the child and the parents. Once the child has begun to take medication, the therapist should monitor the child's progress on a regular basis.



The Brain and Anxiety

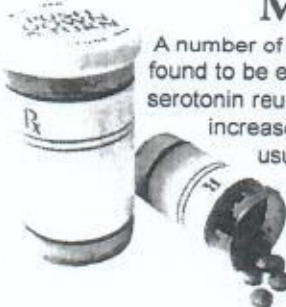
The brain responds to anxiety much as it responds to fear, by sending out two sets of signals to different parts of the brain.

The first goes to the cerebral cortex, the cognitive part of the brain, which processes the details and tries to understand the perceived threat. The other set of signals goes directly to the amygdala, a small almond-shaped structure that is sometimes referred to as the emotional control center of the brain. The amygdala sets the fear response in motion, readying the body for quick action long before the cognitive part of the brain comprehends just what is wrong. This signals the heartbeat to increase and diverts blood from the digestive system to

the muscles for quick action, even when no action is needed. Stress hormones and glucose flood the blood stream. Anxiety disorders develop when the amygdala etches this response pattern onto the brain, pairing it with specific people, events, or other stimuli.

The neurotransmitter serotonin seems to play an important role in counteracting the anxiety/stress response in the brain. Many of the current medications for anxiety disorders make more serotonin, a mood regulator, available to the brain. Other treatment approaches are examining drugs that affect different neurotransmitters and brain chemicals, such as GABA, gamma-aminobutyric acid, and Substance P. A new research tool, magnetic resonance spectroscopy, has been used by scientists to measure brain levels of GABA and other substances.

Medication and Generalized Anxiety Disorder



A number of different types of medications have been found to be effective in treating GAD. Selective serotonin reuptake inhibitors (SSRIs), which effectively increase the amount of serotonin in the brain, are usually the drug of choice. Among the SSRIs that are widely used are fluoxetine (Prozac), sertraline (Zoloft), and paroxetine (Paxil). Tricyclic antidepressants, including imipramine (known as Tofranil), and a group of drugs called benzodiazepines (e.g., Diazepam, widely known as Valium),

are among other medications that have been used.

In October 2004, the Food and Drug Administration warned that use of antidepressant drugs, including SSRIs, may increase the risk of suicidal ideation and suicidal behavior in a small number of children and adolescents. The risk appears to be greatest in the first few weeks of usage, before the medication has become fully effective. It is imperative that parents and teachers be alert to any change in behavior that might suggest that the child is at risk of suicidal behavior, such as agitation, restlessness, or increased irritability; it is important to ask directly about thoughts about suicide.

Resources for Helping Children and Teens with Generalized Anxiety Disorder

Books for Teens

Coping with Anxiety and Panic Attacks. Jordan Lee and Carolyn Simpson, Rosen Publishing Group, 1997

The Anxiety Workbook for Teens. Lisa M. Schab, Instant Help Publications, 2005

Books for Younger Children

Let's Talk about Feeling Nervous. Susan Kent, PowerKids Press, 2003

I Bet I Won't Fret! Timothy A. Sisemore, Instant Help Publications, 2004

Books for Parents

Your Child: Emotional, Behavioral, and Cognitive Development from Birth through Preadolescence. AACAP and David Pruitt, HarperCollins, 1998

Your Adolescent: Emotional, Behavioral, and Cognitive Development from Early Adolescence through the Teen Years. AACAP, HarperCollins, 1999

The Worried Child: Recognizing Anxiety in Children and Helping Them Heal. Paul Foxman, Ph.D., Hunter House Publishers, 2004

Books for Professionals

Tools & Techniques for Helping Children With Generalized Anxiety Disorder. Timothy A. Sisemore, Instant Help Publications, 2005

Phobic and Anxiety Disorders in Children and Adolescents: A Clinician's Guide to

Effective Psychosocial and Pharmacological Interventions. Thomas H. Ollendick and John S. March (Eds.), Oxford University Press, 2003

Anxiety Disorders in Children and Adolescents: Research, Assessment and Intervention. Wendy K. Silverman (Ed.) et al, Cambridge University Press, 2001

Anxiety Disorders in Children and Adolescents. (2d ed.) Tracy L. Morris and John S. March (Eds.), Guilford Press, 2004

UNDERSTANDING DYSGRAPHIA

What is dysgraphia?

Dysgraphia is a specific learning disability that affects how easily children acquire written language and how well they use written language to express their thoughts.

Dysgraphia is a Greek word. The base word *graph* refers both to the hand's function in writing and to the letters formed by the hand. The prefix *dys* indicates that there is impairment. *Graph* refers to producing letter forms by hand. The suffix *ia* refers to having a condition. Thus, *dysgraphia* is the condition of impaired letter writing by hand, that is, disabled handwriting and sometimes spelling. Impaired handwriting can interfere with learning to spell words in writing. Occasionally, but not very often, children have just spelling problems and not handwriting or reading problems.

What causes dysgraphia?

Research to date has shown orthographic coding in working memory is related to handwriting. *Orthographic coding* refers to the ability to store unfamiliar written words in working memory while the letters in the word are analyzed during word learning or the ability to create permanent memory of written words linked to their pronunciation and meaning. Children with dysgraphia do not have primary developmental motor disorder, another cause of poor handwriting, but they may have difficulty planning sequential finger movements such as the touching of the thumb to successive fingers on the same hand.

Does dysgraphia occur alone or with other specific learning disabilities?

Children with impaired handwriting may also have attention-deficit disorder (ADHD)—inattentive, hyperactive, or combined inattentive

and hyperactive subtypes. Children with this kind of dysgraphia may respond to a combination of explicit handwriting instruction plus stimulant medication, but appropriate diagnosis of ADHD by a qualified professional and monitoring of response to both instruction and medication are needed.

Dysgraphia may occur alone or with dyslexia (impaired reading disability) or with oral and written language learning disability (OWL LD, also referred to as selective language impairment, SLI).

Dyslexia is a disorder that includes poor word reading, word decoding, oral reading fluency, and spelling. Children with dyslexia may have impaired orthographic and phonological coding and rapid automatic naming and switching. *Phonological coding* refers to coding sounds in spoken words in working memory. Phonological coding is necessary for developing phonological awareness—analyzing the sounds in spoken words that correspond to alphabet letters. If children have both dysgraphia and dyslexia, they may also have difficulty in planning sequential finger movements.

OWL LD (SLI) are disorders of language (morphology—word parts that mark meaning and grammar; syntax—structures for ordering words and understanding word functions; finding words in memory, and/or making inferences that go beyond what is stated in text). These disorders affect spoken as well as written language. Children with these language disorders may also exhibit the same writing and reading and related disorders as children with dysgraphia or dyslexia.

Why is diagnosis of dysgraphia and related learning disabilities important?

Without diagnosis, children may not receive early intervention or specialized instruction in all the

Understanding Dysgraphia – Page 2

relevant skills that are interfering with their learning of written language. Considering that many schools do not have systematic instructional programs in handwriting and spelling, it is important to assess whether children need explicit, systematic instruction in handwriting and spelling in addition to word reading and decoding. Many schools offer accommodations in testing and teaching to students with dysgraphia, but these students also need ongoing, explicit instruction in handwriting, spelling, and composition. It is also important to determine if a child with dysgraphia may also have dyslexia and require special help with reading or OWL LD (SLI) and need special help with oral as well as written language.

What kinds of instructional activities improve the handwriting of children with dysgraphia?

Initially, children with impaired handwriting benefit from activities that support *learning to form letters*:

- playing with clay to strengthen hand muscles;
- keeping lines within mazes to develop motor control;
- connecting dots or dashes to create complete letter forms;
- tracing letters with index finger or eraser end of pencil;
- imitating the teacher modeling sequential strokes in letter formation; and
- copying letters from models.

Subsequently, once children learn to form legible letters, they benefit from instruction that helps them develop *automatic letter writing*, using the following steps to practice each of the 26 letters of the alphabet in a different order daily:

- studying numbered arrow cues that provide a consistent plan for letter formation;
- covering the letter with a 3 x 5 card and imaging the letter in the mind's eye;

- writing the letter from memory after interval that increases in duration over the handwriting lessons;
- writing letters from dictation (spoken name to letter form); and
- writing letters during composing for 5 minutes on a teacher-provided topic.

Students benefit from explicit instruction in spelling throughout K–12:

- initially in high frequency Anglo-Saxon words;
- subsequently in coordinating the phonological, orthographic, and morphological processes relevant for the spelling of longer, more complex, less frequent words; and
- at all grade levels in the most common and important words used for the different academic domains of the curriculum.

Throughout K-12, students benefit from strategies for composing:

- planning, generating, reviewing/evaluating, and revising compositions of different genre including narrative, informational, compare and contrast, and persuasive; and
- self-regulation strategies for managing the complex executive functions involved in composing.

Do children with dysgraphia make reversals or other letter production errors?

Some children do make reversals (reversing direction letter faces along a vertical axis), inversions (flipping letters along a horizontal axis so that the letter is upside down), or transpositions (sequence of letters in a word is out of order). These errors are symptoms rather than causes of handwriting problems. The automatic letter writing instruction described earlier has been shown to reduce reversals, which are less likely to occur when retrieval of letters from

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memory and production of letters have become automatic.

What kind of instructional strategies improve spelling of children with dysgraphia?

If children have both handwriting and spelling problems, the kinds of handwriting instruction described earlier should be included along with the spelling instruction.

Are educators in public schools identifying children with dysgraphia and providing appropriate instruction in public schools?

In general, no. Although federal law specifies written expression as one of the areas in which students with learning disabilities may be affected, it does not clearly identify the transcription problems that are the causal factors in dysgraphia—impaired handwriting and/or spelling—for impaired written expression of ideas. Some of the tests used to assess written expression are not scored for handwriting or spelling problems and mask the nature of the disability in dysgraphia. Content or ideas may not be impaired. All too often, the poor writing or failure to complete writing assignments in a timely fashion or at all is misattributed to lack of motivation, laziness, or other issues unrelated to the real culprit—dysgraphia. Children who are twice exceptional—gifted and dysgraphic—are especially under-diagnosed and underserved. Teachers mistakenly assume that if a student is bright and cannot write it is because the student is not trying.

Are there research-supported assessment tools for diagnosing dysgraphia?

Yes. See Berninger (2007a) and Milone (2007) below for assessing handwriting problems associated with dysgraphia. Also, see Berninger (2007b) and Berninger, O'Donnell, and Holdnack (2008) for using these tests and other evidence-based assessment procedures in early

identification, prevention, and diagnosis for treatment planning and linking them to evidence-based handwriting and spelling instruction (also see Troia, 2008).

In summary, dysgraphia is a specific learning disability that can be diagnosed and treated. Children with dysgraphia usually have other problems such as difficulty with spelling and written expression, as well as dyslexia and, in some cases, oral language problems. It is important that a thorough assessment of handwriting and related skill areas be carried out in order to plan specialized instruction in all deficient skills that may be interfering with a student's learning of written language. For example, a student may need instruction in both handwriting and oral language skills to improve written expression. Although early intervention is, of course, desirable, it is never too late to intervene to improve a student's deficient skills and provide appropriate accommodations.

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The Genetics of Tourette Syndrome: How it Occurs in Families & Whom Might be Affected

The Tourette Syndrome Association appreciates greatly the professional guidance and expertise provided by David Pauls, Ph.D. and Jeremiah Scharf, M.D., Ph.D. in the development and revision of this brochure.

There are more than 3,000 inherited disorders known to geneticists, and among them is Tourette Syndrome (TS). As you read this booklet, please bear in mind that while it contains the most up-to-date information that we have about the inheritance of TS, it by no means represents the final answer.

Tourette Syndrome (TS) occurs everywhere and affects people of all ethnic groups. Typically TS begins in childhood, is lifelong but is not a life-threatening condition. In the vast majority of cases, symptoms are mild to moderate, and often decrease by early adulthood.

Researchers have made major strides in understanding how TS occurs in families. Work now being carried out by NIH and TSA-funded genetic researchers holds real promise for providing us with a more complete picture of the mode of inheritance and causes of TS. Moreover, now that the human genome has been sequenced completely, that information will ultimately reveal the location and function of all of the genes that determine inherited human characteristics and disorders. When that happens, scientists will know much more precisely about the causes of these conditions and how to limit their effects.

What is Tourette Syndrome?

Tourette Syndrome is a neurobehavioral disorder that produces involuntary motor movements and vocalizations known as tics. Although the symptoms of TS can emerge at any time (usually between the ages of 2-18), the typical age at onset is between 6 and 9 years. While the causes are still unknown, one theory is that TS is a disorder of the "boundary" that normally separates inner thoughts and functions from outward behavior.

TS typically persists throughout life, and its severity varies, ranging from mild symptoms that do not disrupt growth or development to severe symptoms that can be quite impairing and cause considerable difficulty for some individuals. Currently, the best estimate of the prevalence among children and adolescents of this more impairing form is 1 per 1,000 individuals. Recent studies have suggested that the prevalence of the milder forms of TS may be much higher than previously thought, approaching 0.6% of the general population.

Studies have shown that TS does not progressively worsen throughout life, but usually peaks during late childhood to late adolescence. In the vast majority of cases, symptoms begin to diminish by early adulthood.

There are no medical tests for diagnosing TS. A diagnosis is made by taking a medical history and clinical observation based on medically agreed upon criteria. For a diagnosis,

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both motor and vocal tics must be present and persist for a year or more.

TS and Inheritance

In the overwhelming majority of cases TS is inherited. Thus, the vulnerability to having TS symptoms is passed down from parent to child. This inherited susceptibility to TS does not necessarily mean that the offspring will invariably develop symptoms. In other words, inheriting a genetic vulnerability to TS may not result in any symptoms at all. On the other hand, it is likely that a range of symptoms will be expressed to some degree.

Gender appears to play a part in the way the genes that cause susceptibility to TS express themselves. Thus, tics are 2-3 times as likely to occur among the sons of a parent with TS compared to daughters. However, daughters are 2-3 times more likely than the sons to have obsessive-compulsive traits without tics. Similarly, other male relatives of someone with TS are more likely to have tics, while this same person's female relatives are more likely to have obsessive-compulsive behaviors.

Because a person may carry susceptibility genes for TS but not show any symptoms, other factors have been suggested as influencing whether TS symptoms appear. Such factors might include events during pregnancy or around the time of delivery. The fact that TS and its related conditions do not occur in some persons who are carrying a genetic susceptibility does not mean that the children of those asymptomatic individuals are necessarily at lower risk for developing TS and associated conditions. In this situation, the susceptibility genes can still be passed to

some of their children, and their offspring are at increased risk for developing TS and associated conditions compared to the risk in the general population. In order to determine what the risk to children is in these situations, very careful family histories need to be taken by a knowledgeable professional to determine the probability that the unaffected individual is truly carrying TS susceptibility genes. Only when that is done, is it possible to provide estimates of risk to their children.

Conditions Associated with TS

Researchers believe that some transient and chronic tic disorders are conditions caused by the same genes that are responsible for causing TS, but these conditions are milder in expression. Emerging in childhood, a chronic tic can be either vocal or motor and persists for a year or more. A transient tic begins in childhood or adolescence, but typically goes away within a year. The increased frequency of chronic tic disorders among relatives of persons with TS provides strong evidence that both are manifestations of the same genetic underpinnings. Current studies suggest that most forms of chronic tic disorders and some forms of transient tic disorders are caused by the same genetic factors that are responsible for TS. Chronic tics and transient tics are believed to be milder forms of TS. However, it is possible that individuals with either of these conditions still can experience fairly disabling symptoms.

The chance or "risk" of chronic tic disorder occurring in a relative of someone who has either TS or chronic tics ranges from 10 to 17%. This is a far higher figure than the 1-2% frequency of chronic tics among non-TS families in the general population. These percent-

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ages indicate that there is a common genetic basis for both TS and chronic tic disorder.

Perhaps the strongest evidence of a common genetic basis for TS and chronic tic disorder comes from studies of identical and fraternal twins. (Identical twins carry the same genetic endowment while fraternal twins are genetically no different from siblings born at different times.) When one identical twin has TS or chronic tic disorder, the chance of the other twin having either TS or chronic motor tics is 77%. By comparison, only 23% of the fraternal twins of persons with TS or chronic tic disorder have either TS or chronic tics.

Obsessive-Compulsive Behaviors (OCB)

Symptoms of another disorder that appears to be genetically related to TS include obsessive-compulsive behaviors. These may be involuntary repetitive, intrusive and unwanted thoughts or ritual-like activities that may be mild or can cause distress and interfere with daily life. These behaviors may involve a compulsive need for symmetry such as aligning shoes in an exact manner or "evening up" rituals. Evidence of a common genetic basis for TS and OCB is the fact that at least 35% of persons with TS and 10% of their relatives have such traits, with only about 2-3% of the general population exhibiting OCB. Also, the full-blown Obsessive-Compulsive Disorder (OCD) occurs three times more often among the female relatives of persons with either TS or chronic motor tics than among their male relatives.

Attention-Deficit Hyperactivity Disorder (ADHD)

Another condition that occurs frequently among people with TS, chronic tics and

OCB is Attention-Deficit Hyperactivity Disorder, or ADHD. It has been noted that attention deficits and hyperactivity occur in some children who later go on to develop tic disorders. However, unlike the confirmed genetic connection between TS and OCB, it is less certain that either ADHD or milder forms of hyperactivity/attention problems are genetically related to TS. Thus, some studies have found evidence of a genetic relationship between TS and ADHD, while others have found no greater frequency of ADHD among the relatives of persons with TS than among the relatives of persons without TS. Current thinking is that some forms of ADHD, but not all, may indeed share some of the same susceptibility genes as TS. A definitive answer to this question cannot be made until these genes are specifically identified.

How TS is Inherited

Early family studies of TS inheritance suggested that TS, chronic motor tics and OCB might be transmitted through families in an autosomal dominant pattern. That occurs when either the mother or the father was affected with TS or chronic tics or OCB then that parent transmitted one of these disorders to one or more of their children. The simplest genetic model to explain such a mode of transmission is one that posits a *single TS susceptibility gene* that has a major effect on the manifestation of TS and associated conditions. The assumption is that the affected parent passes on this gene to one or more of his/her children, and those children then have an increased risk for developing TS. It is important to remember that, even in this scenario, the "TS gene" will not necessarily be passed on to all children.

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However, more recent studies of TS inheritance suggest that the underlying genetic mechanisms are much more complex than previously thought, and that there is not just one "TS gene." In fact, for most individuals, it is likely that many genes, in concert with non-genetic, environmental factors, all join together to increase a person's susceptibility for expressing TS and related conditions. Furthermore, in many cases, these susceptibility genes may be inherited from both sides of the family. This does not mean that TS is any "less genetic". It just means that it is highly likely that there will be several genes that may increase the risk for having TS and related conditions. In order to understand fully the underlying genetics of TS, scientists first must find all of these genes to determine whether and how they interact to cause increased risk in those who have inherited them.

Conclusion

TS, chronic tics and OCB affect millions of persons throughout the world. None of these conditions is life threatening, and in the vast majority of cases, they are mild and often lessen considerably by adulthood. Major strides have been made in revealing the patterns in which susceptibility to these disorders is inherited. Additionally, medications and other treatments have proven effective in reducing many of the symptoms of TS.

Identification of one or more of the genes responsible for causing TS and its associated disorders is likely to occur in the near future. Once we have those genes in hand, further research will clarify just how they cause these disorders, and knowing this should lead to improved treatments and an eventual cure.

COMMON QUESTIONS ABOUT TS AND GENETICS

The risk factors cited here are derived from very careful and complicated analyses of family histories taken from hundreds of families not unlike those of the reader. This way of determining probabilities is called "empirical risk figures." Because there is no TS diagnostic test, this is the method that must be used by knowledgeable genetic professionals.

Q. What is the likelihood of a child's having TS or one of its related disorders if the child's mother/father has TS?

If a father or mother has TS and comes from a family in which other members have TS or one of its related conditions, there is a significantly increased risk that his or her child will have either TS or one of its related conditions. The risk is different for boys and girls. Specifically, the chance that a son will develop TS is approximately 10-15%. Furthermore, the chance that he will manifest chronic tics is about 15-20%, and the chance that he will have OCB without tics is approximately 5-10%. Thus, the overall risk that a son will express something in the TS spectrum is approximately 40-45%. The risks for a daughter are approximately 3-5% for TS, 10-15% for chronic tics and 10-20% for OCB without tics. The overall risk for a daughter is approximately 25-35%.

These risk factors increase further when both parents have TS and/or OCD. In this situation, the offspring risk for TS may be as high as 25-50%, with the risk for chronic motor tics an additional 15%. The overall risk of a TS/OC spectrum condition for a child of two parents with TS and/or OCD

may be 70-90%. It should be noted, however, that these recurrence rates in bilineal families are from a very small study in a single clinical sample, and thus may be overestimates of true risk. It is also important to note that, in general, most individuals who inherit a genetic susceptibility for TS have very mild conditions for which they do not seek medical attention.

Q. What is the likelihood of a child having TS when the parents already have a child with TS or a related disorder?

If the second child is not an identical twin, the risks are the same as those described above. However, if the child with TS is an identical twin, there is a 75%-90% chance that the second twin will also have one of these disorders.

Q. If neither parent appears to have TS, OCB or chronic tics, what is the chance that this couple will have a child with TS?

In this case, determining the risk to the child requires that a careful family history be taken to determine if and how many relatives have TS and/or related conditions. If there are affected relatives, the risks for TS, chronic tics and/or OCB will decrease depending on how distantly related the affected relative is to the expected child. In general, the risk to second degree relatives (grandchildren, nieces and nephews) will be about half as great as those described above for children of TS affected parents. The risk to third degree relatives (first cousins, great grandchildren, great nieces and nephews) will be reduced even more. These risks will vary depending on the sex of the affected relatives and the sex of the antici-

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pated child. If there is no family history of TS, tics or OCB, the risk to the child will be no greater than that of anyone else in the general population.

Q. Can the severity of TS in an offspring be predicted based on the severity of the TS affected parent?

Unfortunately, at this time it is not possible to predict the severity of TS or its associated disorders either prenatally or in young children. However, in the vast majority of cases, TS, chronic tics, and OCB are mild, and most long-term studies of persons with these disorders suggest that symptoms decrease with age, and are often essentially unnoticeable by adulthood.

Q. Putting genetics aside, are there risk factors in the shared family environment that can be managed so as to reduce the likelihood that symptoms will develop?

Because studies have not identified any clear risk factors for TS or its related conditions in the shared familial environment, there are no measures that can be taken to prevent the occurrence of symptoms. However, it is important to remember that TS symptoms are involuntary, and children and adults do not "choose" to manifest these symptoms. Patience, understanding, and a supportive family are important ways to ease a person's discomfort and concerns.

Q. Are there any genes that have been proven definitively to cause TS?

While there are some encouraging leads, at this writing, no genes have been consistently proven to increase the risk of developing

TS. The TSA International Consortium for Genetics, an NIH- and TSA-funded collaboration of TS geneticists worldwide, have identified a region of the human genome on chromosome 2 that appears to harbor a TS susceptibility gene, but the specific gene has yet to be identified. Another NIH and TSA-funded investigator has identified a few TS individuals with rare mutations in a gene called *SLITRK1*. Currently these changes seem to be present in only 1 in 1000 cases of TS (0.1%) and analysis of this gene has not yet been demonstrated to be useful outside of the research setting. Nonetheless, ongoing research projects from these and other groups offer great promise in identifying more definitive TS susceptibility genes in the coming years.

Q. Can TS be diagnosed with a genetic test?

Until specific TS susceptibility genes are verified, a diagnostic test cannot be developed. However, the current accelerated pace of TS genetics research holds promise for the development of a diagnostic test.

Q. The adult child of a parent with TS appears to be unaffected. What is the risk to that adult child's offspring?

Once again, it is necessary to obtain a detailed family history to obtain more accurate estimates of risk. In this case, what would have to be determined first is the probability that an adult offspring inherited the genes from the affected parent. This probability is dependent upon factors such as the sex and age of the adult offspring and the sex of the affected parent. Once that probability has been estimated, it is included in the estimate of risk to children of this unaffected adult. Individuals wanting this type of information should seek

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the guidance of a qualified genetic counselor who is knowledgeable about the familial risks for TS and related conditions.

Q. What are the chances that the child of an unaffected sibling of someone with TS will have TS?

The risk factors are the same as described above.

Q. Can other factors cause TS?

Although genetic factors clearly contribute to the development of TS, genetics are not the entire story. Non-genetic factors are also important, both as causes and modifiers of TS. Developmental and environmental factors are likely responsible for the wide range of symptoms observed among different individuals, including the course, severity, and type of symptoms, as well as the development of associated disorders such as OCD and ADHD. Studies of non-genetic factors have primarily focused on stressful and other events during

the prenatal, perinatal, or early life periods, particularly those which could cause damage to the developing brain. Although there are little data as yet in this area and much of these data are retrospective, studies have indicated that children with tics or TS have somewhat higher rates of maternal/obstetric complications such as traumatic birth, forceps delivery, or hypoxia when compared with the general population. In particular, prenatal exposure to nicotine and/or alcohol appears to increase both the severity of tics and the risk of developing OCD. The results of two studies examining identical twins, in which one twin had TS and the other did not, showed decreased birth weight in the twin with TS compared to the unaffected twin. In the general population, decreased birth weight is often associated with a compromised fetal environment. Although not yet conclusive, these studies do point to the potential importance of environmental factors that affect early brain development in the appearance and expression of TS symptoms.

GLOSSARY

Autosomal dominant: A pattern of genetic inheritance in which a disease is caused by an alteration of one copy of a gene on one of the 22 non-sex related human chromosomes. With diseases and disorders caused by this inheritance pattern, there is a 50/50 chance of the condition being passed on from one parent to a child. Note: TS is no longer thought to be inherited by this pattern, except possibly in very rare instances.

Bilineal inheritance: Inheritance of genetic risk factors from both parents.

Family study: When a genetically caused disorder is investigated in members of a family to determine how the disorder is inherited.

Gene: A unit of hereditary material that determines a particular trait or characteristics such as a medical condition or hair or eye color. All genes consist of a chemical substance known as deoxyribonucleic acid, or DNA. In any particular gene, the DNA occurs in a specific, sequential order that determines the effects of the gene.

Gene of major effect: A gene that chiefly determines a trait or characteristic, such as hair color or an inherited disorder.

Genome: The complete array of all human genes which is found in nearly all cells in the body. The human genome consists of 30,000-40,000 genes.

Twin study: A study in which the occurrence of a disorder or trait is studied in identical and fraternal twins in order to determine whether the trait is genetically determined.

Should readers have additional questions, they should consult directly with a professional knowledgeable in TS genetics. The information contained herein is provided solely to clarify current thinking about the genetics of TS. Indeed, the genetic research presently being carried out may well provide new data that could change our perceptions of the inheritance of this disorder. Should that occur, TSA will endeavor to provide that new information to its members in a timely manner.