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TOURETTE SYNDROME AND BEHAVIOR

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HELPFUL HINTS FOR MANAGEMENT OF CHILDREN WITH TS ASSOCIATED BEHAVIOR PROBLEMS

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Tourette syndrome and behavior introduction

Tourette Syndrome (TS) has classically been defined as a disorder of motor and vocal tics. However, in recent years there has been a growing awareness of various other behavioural problems which are frequently associated with TS. These "associated disorders" may include: obsessive-compulsive behaviours, attention deficits and hyperactivity; impulsive, aggressive and explosive behavioural patterns, self-injurious behaviours; abnormal sleep patterns; and infrequently, inappropriate sexual behavior. Learning disabilities, although not behavioural problems in themselves, may also contribute to the overall adjustment problems faced by a TS patient.

At the present time genetic research indicates that obsessive-compulsive behaviours may be a primary manifestation of the TS gene. That is to say, the gene may express itself in a particular individual either by tics or by obsessive-compulsive behaviours – or by both. Some geneticists believe that attention deficit disorder and hyperactivity may also be transmitted by the same gene. This direct genetic link, however, is more controversial. Researches hope that within the next few years continuing genetic investigations will clarify whether all the "associated disorders" mentioned above are an integral part of TS, or are instead the secondary results of living with this complex and difficult disorder.

Behavioral difficulties, whether primary or secondary, occur against the familiar backdrop of the TS patient's chronic struggle to control, suppress or modify his or her tics. These efforts inevitably take their toll on the concentration levels and result in tension build up.

At times this pattern of suppression leading to tension creates a vicious cycle. Tension and stress will cause more tics, which, in turn, increase tension. Thus, concern about social and work-related consequences of increased symptoms may contribute to chronic states of anxiety, depression or social withdrawal.

Given this chronic struggle, it is not surprising to find a patient's thoughts constantly focused on problems of control and loss of control. Additionally, 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 as well as social and personal functioning.

Finally, it should be recalled that normal childhood and adolescent behaviours 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 behaviours 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 in this introduction 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. In the following sections specific behaviours will be discussed in greater detail. Please bear in mind several points as you read on. 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 behavioural 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. Psychological 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

As already mentioned, there is increasing evidence that obsessive-compulsive (OC) behavior (the extreme form is termed obsessive-compulsive disorder, OCD) may be one way in which the TS gene shows itself – with or without motor and vocal symptoms.

Obsessions are defined as recurrent, intrusive, unwanted thoughts which provoke anxiety. Compulsions are defined as voluntary motor acts which are repetitive, ritualistic and which are performed in order to reduce specific anxiety – at times, to rid the patient of an unwanted thought. Even for experts distinguishing between a complex motor tic and a compulsion can be difficult at times. However, response to medication may help in the distinction, because 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 as with TS, 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 compulsion are: the need for "evening things up" (touching an object with one hand necessitates touching it with the other), continually counting things unnecessarily; checking things over and over (checking many times to see if the stove is turned off); performing simple actions over and over again (turning the light switch on and off five times instead of once). 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 doing it.

Obsessive-compulsive symptoms may respond to behavior modification therapy which is a type of treatment using conditioning techniques. This therapy is more effective for compulsions than for pure obsessions. 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 much impact on OC symptoms. Prozac (fluoxetine) and Anafranil clomipramine), two relatively new antidepressants, have both been shown to be effective medications for the treatment of OCD. Other medications may be used to strengthen or bolster a partial response to one of these medications. While these drugs do not seem to have much impact on tics, they may be of benefit for some associated difficulties with impulse control.

The spectrum of OC behaviours remains to be clarified. Eating disorders, alcohol and drug abuse, compulsive gambling, compulsive shopping, and compulsive sexual behaviors are among the behaviours currently being studied.

ATTENTION-DEFICIT HYPERACTIVITY DISORDER

The association of attention deficit hyperactivity disorder (ADHD) with TS varies considerably among individuals. The question of whether ADHD is a primary manifestation of TS has yet to be settled and the answer awaits further knowledge about the TS gene. Simply defined, ADHD is a collection of signs and symptoms which include impairment of ability to focus and sustain attention for a variety of activities 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 in distraction 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 considerable difficulties controlling their aggressive behaviours with peers and authority figures. At times, patterns of anti-social behaviours can be seen.

Receiving a diagnosis of ADHD may be complicated by the presence of tics which, in themselves, may impair concentration. Also 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, psychological 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 following the use of stimulant medications (e.g. Ritalin, Cylert, Dexedrine) which were prescribed because they are effective for the treatment of ADHD symptoms. Therefore, the more conservative approach has been to avoid prescribing stimulant medications for any patient with either a personal or family history of tics. Medications such as Halidol (halperidol) or Orap (pimozide) both of which help to control tics, are not usually of much benefit in the treatment of ADHD symptoms. Alternatives to the stimulant medications include Tofranil (imipramine), Norpramin (desipramine), Pamelor (nortriptyline) and Catapres (clonidine). Unfortunately, these medications are usually not quite as effective as stimulants in helping to improve concentration. Therefore, there are times when stimulants may be the treatment of choice for a TS client 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. This, understandable concern over the possible worsening of TS symptoms due to taking stimulants must be balanced against the potential benefits of those medications for 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 patients with TS and ADHD may first come for treatment because of the tic disorder, it is our observation that the ADHD symptoms actually may be much more problematic for them. We all hope that continued research into the relationship between TS and ADHD will yield more effective treatments for the ADHD symptoms as well as the tics.

IMPULSIVE, AGGRESSIVE, EXPLOSIVE AND OTHER UNUSUAL BEHAVIORS

Impulsive behavior is one characteristic of attention deficit hyperactivity disorder. While we all at one time or another may have the urge to interrupt, to test wet paint by touching it, or to dart across the street against the light, we usually resist these urges. The person with TS however, may not be able as easily to resist these same impulses.

In addition many of these same patients have what might best be described as 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. Typically, these individuals greatly regret their explosive outbursts. Between outbursts they will be 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. In extreme cases, Tegretol (carbamazepine), an anti-seizure medication which stabilizes mood and can decrease explosive, violent behavior, may be effective. Behavior therapy may also be helpful in these situations.

Self-injurious behaviours afflict a small minority of TS patients. 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 behaviours 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 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.

In rare instances, inappropriate sexual behaviours (e.g. exhibitionism, voyeurism) may be associated with TS. There are several surveys which indicate that these behaviours occur somewhat more with TS patients than in the general population. However, it must be emphasized that they are uncommon in TS and certainly not characteristic of

the typical person with TS. While these behaviours have not been studied extensively, it is probable that they represent aspects of both obsessive-compulsive behavior and poor impulse control.

SLEEP DISORDERS

Sleepwalking, increased night time wakening, bed-wetting, night terrors and motor and phonic tics which occur during sleep have all been reported as frequent 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. Others report an improvement subsequent to taking medications.

LEARNING DISABILITY

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 specific treatment recommendations.

ADDITIONAL RESOURCES

The Tourette Syndrome Association (TSA) maintains a comprehensive listing of modestly priced video tapes, medical reprints and general literature for children, families, teachers, nurses and physicians. These materials are relevant to the subjects touched upon in this brochure and can be very helpful to families dealing with the problems of TS and its associated behaviours. For further reading, you may want to request a free copy of TSA's Catalogue of Publications and Films from: Tourette Syndrome Association, 42-40 Bell Blvd., Bayside NY 11361, 718/224-2999.

Helpful hints for management of children with TS associated behavior problems

Managing children with both TS and the associated problem behaviours 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 behaviours. TS associated behaviors have their basis in physical causes just like motor and vocal tics. Therefore, a child exhibiting the associated behaviours is not a "bad" child, but rather may be exhibiting behaviors which are physical manifestations of TS. However, some problem behaviours can be modified or changed and parents need to analyze which behaviours 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 behaviours. 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 of 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 font', 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 work.

REWARDS

With some 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 behaviours. 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 other's provocations. Did you ever think of trying to ignore your child's behaviours that are performed solely to 'push your buttons' or to get his or her own 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 behaviours 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 behaviours 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 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 and remain composed. Keep your voice calm.
4. Try and have the consequence **'fit the crime'** when determining it's duration. When your child no longer cares about the punishment, it may be time to call it off.
5. Surprisingly, **modest but consistent discipline** make a greater impression on children than more severe and less frequent discipline.

SPECIFIC TS ASSOCIATED BEHAVIORS

Following are suggestions about management of specific behaviours sometimes associated with TS. However, we should be aware that each individual is unique and may exhibit only one or several of these behaviours. 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 behaviours. Depending on the degree of impulse control impairment, initially, parents may **need to connect** most desirable and undesirable behaviours 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 behaviours 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 behaviours 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 behaviours 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 and institute a bathroom schedule for the whole family.

Behavior therapists specializing in treating obsessive compulsive behaviours can offer techniques which may decrease some of your child's more problematic behaviours. For instance, in a series of steps, a behavior therapist may try to supportively encourage a child to decrease the amount of time spent on a ritual tapping the bed seven times instead of eight. He/she may suggest setting a timer to get your child out of the shower in 10 instead of 20 minutes. 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 would like to learn more about this type of help, contact the Association for Advancement of Behavior Therapy for the name of a behavior therapist specializing in OC behavior. Address: 15 West 36th St., New York, NY 10018. Telephone: 212-279-7970. You may also want to write to the OC Foundation, PO Box 9573, New Haven, CT, 06535.

CONCLUSION

In summary, the techniques covered here may not address all of your child's problem behaviours. 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.