



TOURETTE SYNDROME ASSOCIATION OF AUSTRALIA, Inc

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PROBLEM BEHAVIOURS

&

TOURETTE SYNDROME

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Tourette Syndrome is a neurological disorder that affects thousands of Australians and is characterised by involuntary body movements and vocalisations called 'tics'.

People with Tourette Syndrome are normal in every other way.

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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.

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 TS patient.

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 psychologi-

cally 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 sus-

tain 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, understand-

able 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 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 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 with TS patients 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 wakening, bedwetting, 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 tics. 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
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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 play-

ing 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 prom-

ised, 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