

Discipline Made Easy

It is possible to get your child to do the right thing without shouting or issuing threats. Here's the secret.

by Marybeth Lambe, M.D.

All parents want their children to be happy and well-adjusted. But parents also want them to be respectful and obedient. Of course, kids-particularly those with attention-deficit disorder-have their own ideas. So, rather than do what's asked of them, these children ignore their homework, torment their siblings, and forget to feed the dog. They leave wet towels on the bathroom floor and dump Legos in the living room. They talk back, whine, sulk, or otherwise misbehave. Each day brings fresh chaos.

Parenting experts have devised all manner of discipline techniques. But when it comes to reining in volatile, easily frustrated kids, it's hard to beat the system devised by Thomas W Phelan, Ph.D., a clinical psychologist in Glen Ellyn, Illinois, and the father of a son who has ADD.

No More Power Struggles

Dr. Phelan's 1995 book, *1-2-3 Magic: Effective Discipline for Children 2-12*, is considered a classic of parenting literature. It's embraced not only by moms and dads, but also by ADD support groups, counselors, and psychiatrists-and no wonder. It offers specific, simple instructions rather than vague psychological concepts, and it has proven to be highly effective.

"1-2-3 Magic circumvents the whole power struggle," says Jean Mills, a social worker from Issaquah, Washington, and the mother of a 14-year-old with ADD. "There is no discussion and no chance to get into a debate with your child. So many of these kids have other issues-and have trouble handling frustration and anger. *1-2-3 Magic* keeps words and emotions to a minimum."

To successfully implement Dr. Phelan's system, parents must differentiate the two kinds of behaviors their children "give" them:

- "Stop" behaviors. Talking back, yelling, teasing, throwing tantrums, and whining are all behaviors

that parents want their children to stop.

- "Start" behaviors. These are things parents want their children to start doing regularly and without reminders -things like doing homework, feeding a pet, going to bed on time, getting up and off to school on schedule, or practicing a musical instrument.

The Counting Technique

Dr. Phelan recommends a range of familiar parenting tools and techniques, including the use of charts (work on no more than three behaviors at once) and timers; more positive feedback and less criticism; and minimizing the number of on-the-spot requests parents make of children. (Even simple requests, such as "walk the dog" or "run this over to the neighbor's," can make ADD kids feel put-upon. Better to let them know ahead of time what is expected of them.)

But the most celebrated component of Dr. Phelan's system is his "counting" technique, which is used to put an end to "stop" behaviors (see "Stopping an Argument in Its Tracks," page 5.)

"Counting" works like this: Each time your child does something he shouldn't, simply hold up one finger and quietly say, "That's one." If the behavior

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Our Mission

The Tourette Syndrome Foundation of Canada is a national voluntary organization dedicated to improving the quality of life for those with or affected by Tourette Syndrome through programs of: education, advocacy, self-help and the promotion of research.

Our Vision

All People who have Tourette Syndrome will lead quality lives as accepted and valued members of an informed, tolerant society.

Contributing Authors

Brigitte Heddle
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Jennifer Robertson

President's Message

In our front page story we reprint an article from May 2006 issue of ADDitude magazine. We were fortunate to receive permission to reprint this article as their normal policy is "not within 6 months of their original printing." Thank you, Paula Grande.

The article titled "Discipline made Easy" is by Marybeth Lambe, M.D. and encourages use of techniques from a system devised by Thomas W. Phelan, Ph.D. and explained in his 1995 book "*1-2-3 Magic: Effective Discipline for Children 2-12.*"

"*1-2-3 Magic*" differs significantly from behaviour management techniques put forward by Dr. Ross Greene, whose techniques generally involve talking things over with the child. In this article, Dr. Phelan states that we are not really dealing with small adults and that discussion won't necessarily lead to a resolution.

TS in the News reports on a Toronto Star story about an individual with TS. Originally we had planned to report on a Free Press article about a missing girl whose description included skin colour, height, weight, hair characteristics, clothing and "she has a mild form of Tourette's syndrome and attention deficit hyperactivity disorder (ADHD.) I was interested to know how the Staff writer considered the TS and ADHD information would be useful in identifying the girl. After four e-mails to the Free Press over 1 ½ months I haven't received a response. Perhaps we will have more on this story next time.

Brigitte Heddle's article on "neurofeedback" being used to treat ADHD is interesting and raises the question about "neurofeedback" and TS. Perhaps we can explore the possibilities in a future edition.

We again have excellent articles by Dr. Mary Jenkins and Jennifer Robertson as well as number 6 in the CPRI Brake Shop series "Putting the Brakes on." Disinhibited Thoughts will be back next time.

Thanks to all who have contributed to this newsletter.

Ray

Exceptional Children – Ordinary Schools: Getting the Education You Want for Your Special Needs Child

Dr. Norm Forman.

Markham: Fitzhenry and Whiteside Limited, 2005

Exceptional Children – Ordinary Schools is a handbook for parents of special needs children who require educational assistance. It pertains to children with any condition which might impair their ability to learn normally, including Tourette Syndrome, Attention Deficit Hyperactivity Disorder, Obsessive Compulsive Disorder, Autism, and Asperger's, among others. Forman's goal is to provide parents with information that will help them successfully advocate for their child to obtain the educational assistance he or she needs to succeed at school.

He has compiled an indispensable guide to dealing with the school system from a parent's point of view, covering topics such as: how to compile relevant information about a child's learning disability in order to facilitate the process of getting him or her educational assistance; the roles and duties of various school personnel; effective communication and conflict resolution skills; negotiating with teachers and principals to obtain services despite potential obstacles such as low funding and time constraints; school board procedures for testing, assessing, and placing a special needs child in a correct program; developing an Individual Education Plan for a child; and education laws and rights of parents and children under the Human Rights Legislation and the Canadian Charter of Rights and Freedoms.

Strong emphasis is placed on preserving good relations between parents and school personnel, so that conflicts, frustration and resentment don't harm the child's chance to receive proper assistance. Sample letters, charts, and worksheets are provided for sorting out special needs and their appropriate courses of action.

Forman is an experienced educational psychologist and administrator of a parent advocacy organization in Toronto, positions which have furnished him with 25 years of first-hand experience with special-needs children, the school system and its procedures on how to deal with them, and the role of parent advocacy.

The book is written in straightforward language, and is generally easy to read. It can be a little tedious and repetitive at times, and the case examples and personal anecdotes are surprisingly uncreative and unenlightening, but the information is conveyed effectively nonetheless. Parents of children with special needs who are interested in becoming active in their children's educational program would benefit immensely from reading this book. Teachers and educational assistants, as well as anyone interested in the practice of advocacy or special education programs would also gain some valuable insights from it.

Reviewed by Jennifer Robertson

A young man, 16 years old, is scheduled for a Botox injection near his eye as a treatment for a tic that causes his eye lashes to curl under, resulting in damage to his eyes.

Could you tell us more about this form of treatment and when it should be considered?

Reply

Botox is best known for its use in cosmetic procedures, but in fact, it has been used very effectively for many years as a treatment for certain involuntary movement disorders. An interest in using Botox to treat tics arose due to its good success with other movement problems.

Botox is an agent that is derived from the bacteria that cause botulism food poisoning. The bacteria produce a toxin that can be extracted and purified to use as the product Botox. The Botox used for treatment has a very low dose of the toxin and therefore is safe to use in humans. Botox is injected into muscles in very small quantities and produces temporary muscle weakness at those sites. Because the muscles injected are overactive, the effect of the botox is to suppress the muscles so they are working at a more normal force. The weakness is caused by blocking the release of one of the chemical messengers (acetylcholine) that makes muscles work. Botox is only effective in the muscles that it is injected into and does not have wide spread effects. It takes 3 to 10 days following the injection for the effect to occur and then it generally lasts for approximately 3 to 4 months. To maintain the effect, people usually must have the injections every 3 months.

In the treatment of tics, Botox is used when oral medication has failed. It is generally reserved for a single, persistent tic that has not responded to medication treatments. No more than one tic can be treated at a time, as only a certain amount of Botox can be given at each treatment.

Research studies on Botox for treatment of tics have been done in children and adults whose tics did not respond to usual medications. Most studies have reported improvement in the motor tic treated, although not all studies have shown good improvement. The target areas have included the face (including around the eyes), neck, back, arms, legs, or trunk. Some studies have shown improvement in vocal tics by injecting the vocal cords with Botox.

While Botox works fairly well, its use in treating tics is limited by a number of factors. Firstly, tics change in location over time, so as soon as one tic is suppressed, another one may appear. Secondly, the treatment is given by injection, and many children and adults do not tolerate needles well. Lastly, it is very expensive (\$350 per vial) and must be repeated every 3 to 4 months. Having said all that, in cases of a severe tic that is causing pain or damage (as in our case

above), Botox can be a very effective and successful treatment.

Because Botox is effective only in the muscles that it is injected into, there are no general side effects like drowsiness, dry mouth, or change in weight that may be seen with some of the oral medications. However, in view of the fact that it works by weakening muscles, sometimes if the dose is too strong, people may have excessive muscle weakness. In the case of vocal cord injections, this weakness may impair swallowing and speech. Fortunately, this reverses as the medication wears off.

In conclusion, Botox is a safe and effective treatment for a single, persistent tic that has not responded to usual medication treatment. The Botox is given by needle into the target muscles that cause the tic. The treatment is generally effective for 3 months and then must be repeated. This treatment is costly, but may be considered in cases of a tic that is painful or causing damage such as the severe eye blinking tic.

Dr. Mary Jenkins, MD, FRCPC – Neurologist

TSFC Conference 2006
Four Winds of Change
30 Years of Ticking Together

September 14–16, 2006
Delta Edmonton South Hotel, Edmonton, Alberta

Get practical knowledge and advice

- Dr. Norm Foreman, Author of *Exceptional Children – Ordinary Schools: Getting the education you want for your special needs child*, and Bob Clements will help you become an effective advocate for your child in the education system.
- Dr. Daniel Gorman will provide you with a better understanding of the gambit of medications for the treatment of tics, ADHD and OCD.
- Dr. Cathy Budman will explore rage and TS.
- Dr. Robyn Stephens will describe how sleep problems can affect your child's daytime world.
- Dr. Trina Epstein will give you an understanding of the practical use of Cognitive Behavioral Therapy.
- Hear about new genetic discoveries from Dr. Cathy Barr
- Dr. Bradley Peterson will update you on the latest in imaging.

Kids Club/Teen Club

Here are some activities we are working on!

- Meet Dr. Dunc!
- Go rock climbing at Vertically Inclined or
- Explore the human body or solve a crime at the Telus World of Science
- Kids can join Indiana Lynn and the Cartoonigans gang on a Survivor Game Show
- Teens will become the stars of their own commercial about TS
- Swim, create, play games, find new friends and more!

Discover Edmonton and the TS Community

- Experience western hospitality
- Meet chapter volunteers and national board members from across the country
- Honour award winning members of the TS community

- Come with us Friday night to West Edmonton Mall, the biggest mall in the world, and choose from an evening at Jubilations Dinner Theatre or explore the attractions at WEM

- Saturday dance the night away to the infectious rhythms of Edmonton's own Radiovacana.

- Explore all that Edmonton has to offer!

Educator's Sessions

- Mort Doran, M.D. - Dr. Doran went through life including medical school without knowing anything about his unique characteristics. He wasn't diagnosed with Tourette Syndrome until his mid 30's.
- Susan Conners, M.Ed. – Ms. Conners is the Education Specialist for the Tourette Syndrome Association (TSA) in the United States.

International Symposium on Tourette Syndrome and Other Neurodevelopmental Disorders

See details at www.tourette.ca

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continues, raise two fingers and say, "That's two." If the child still ignores your request, raise three fingers and say, "That's three. Take five." The child then goes (or is escorted) to a five-minute time-out in his room. (If you feel your child is too old for the term "time-out," use another one, like "cool down," "break," "breather," "halt," or "pause.")

STOPPING an ARGUMENT in Its TRACKS

Child: "Can I go out after dinner to play?"

Parent: "No, dear, you still have homework to do."

Child: "I'll do it when I come back in, I promise."

Parent: "Get your homework done first, and then you can go out. If you work hard, it shouldn't take more than half an hour."

Child: "Why can't I just go out now? I'LL DO MY STUPID HOMEWORK LATER!"

Parent: "That's 1."

Child: "I can't wait to grow up and move away so you can't boss me around anymore."

Parent: "That's 2."

Child: "All right, all right, all right." (He sits down to start his homework.)

Adapted from 1-2-3 Magic, by Thomas W. Phelan, Ph.D.
(Parentmagic, Inc)

If your child won't budge, remove *yourself* from the room: Take a brisk walk around the house, read a few pages of a book, lock yourself in the bathroom-but NO talking to your child, even if he tries to follow you! That's it. You don't shout or cajole or explain. It's clear to your child that he has a choice: He can shape up at once or suffer a consequence.

Once the time-out is over, do not rehash the episode or lecture your child about it. It's over.

Praise more, criticize less

What about getting your child to adopt "start" behaviors? The fundamental principle, says Dr. Phelan, is to spend less time criticizing your child, and more time offering praise.

Dr. Phelan's system works, in part because it helps parents avoid two common mistakes: Talking too much and showing too much emotion.

Parents are quick to speak up when a child does something wrong, but not so quick when the child does something right. According to Dr. Phelan, negative feedback undermines a

child's self-confidence, which makes it even harder for him to handle tasks and chores independently. Praise, specific and genuine, feeds a child's self-esteem and willingness to cooperate.

Always be on the lookout for opportunities to offer praise: "Good job on the spelling test, Amy!" or "You cleaned your room up beautifully! And I didn't even have to remind you. Wow!" or "You got ready for school so fast today!" Ideally, says Dr. Phelan, you'll praise your child about four times more frequently than you criticize her. Show, by your words and actions, that you believe your child can manage himself -- and he probably will. Discipline should become less of a problem.

Praise is especially beneficial for children with ADD, who may face relentless criticism from teachers and friends, as well as from their parents. And being more generous with praise helps you enjoy your relationship with your child.

"1-2-3 Magic reminds us not to neglect the positive aspects of parenting," says Becky, a Detroit mom who moderates a support group for parents of ADD kids. "I used to talk only when I was annoyed. Now I try to speak up with praise or make positive connections when things are going well."

As you praise more, fight the urge to "over-parent." That's the term Dr. Phelan uses to describe the pattern of needless correction, supervision, or disciplinary commentary that parents often fall into -- things like "Tie your shoes!" or "Put on your coat!" or "Chew more slowly!"

Despite your good intentions, comments like these irritate and demean your child-and undermine her ability to take care of herself. Your central "message" to your child becomes, as Dr. Phelan puts it: "I have to worry about you so much because you're incompetent; there's not much you can do on your own without my supervision and direction."

Often, it's better for children to learn "start" behaviors on their own -- and if they make mistakes, so be it. "There are times when staying out of problems is the best thing," says Dr. Phelan. "Let the big, bad world teach the child what works and what doesn't." If your daughter keeps forgetting her coat in the winter, for example, maybe you should let her be cold. If she neglects to put her dirty clothes in the laundry hamper, she can go to the party in a soiled dress. If your son forgets his homework, let the teacher keep him late after school to make it up.

In each case, you're letting the *consequences* of your child's mistakes teach him or her the important lesson without having to say a word.

Why the system is so effective

Dr. Phelan's system works, in part, because it helps parents avoid two common mistakes: Talking too much and showing too much emotion. After all, says Dr. Phelan, children are

not "little adults" who can be persuaded to change their behavior. Yelling at or otherwise showing anger to a child does little but escalate the confrontation, leading to what Dr. Phelan calls the "talk-persuade-argue-yell-hit syndrome."

Parents often assume that the more information they give their kids, the more compliant their children will become. The opposite is usually true. Dr. Phelan explains: "When Mom wants Tommy to stop teasing his sister, for example, the simple warning, 'That's one: is clearer and more attention-getting than a recitation of five reasons why teasing is bad. Parental lectures and nagging not only confuse children, they also irritate them -- thus reducing the chances of cooperation."

Whenever you child shows you his schoolwork, Dr. Phelan recommends first noticing something appositve about it and ending your comments with an additional positive remark. For example, before pointing out a calculation mistake, you might offer a compliment ("Wow, you did a terrific job on problem 2 – that was a hard one!") End with more praise: "This graph looks great – you made it really easy to read!"

There's another reason *1-2-3 Magic* is so effective with kids who easily become confused or overly excited. "Moms and dads often share these same characteristics with their children," explains Dr. Phelan. "Mom and dad, in other words, get mixed up by too much talking, and they get upset too quickly. When a challenging child is involved, these parent-child similarities make the task of reasonable discipline almost impossible."

Your child may fight the *1-2-3 Magic* system, especially the first few times you use it. Hang in there. Parents who have tried the system say children respond amazingly well within a week or two -- as long as parents avoid their old patterns of lecturing, arguing, scolding, and so on.

"Give it an honest try!" says Susan, a mother of three who has used *1-2-3 Magic* for three years'. "If you quit too soon, you'll never know what peace *1-2-3 Magic* could have brought you."

Jonathan's transformation

Nancy knows firsthand how hard it is to discipline a child with ADD. The Seattle mom's third-born, Jonathan, now 13, was frequently disobedient, despite taking medication for ADD and oppositional defiant disorder and seeing a cognitive therapist. Nancy and her husband, Steve, first heard about *1-2-3 Magic* when Jonathan was 11. They were skeptical.

"It seemed too easy," recalls Nancy. "The idea of getting a big, strong, angry kid to take a time-out -- well, it didn't seem

likely."

"The first day, Jonathan was more startled than anything," says Steve. "I think we counted him for talking back to us. What got his attention was that we didn't talk at all, just tried to count calmly as the video says to do."

After counting Jonathan to three, Susan says, "Steve led Jonathan up to his bedroom, and he actually sat there! Well, it was not that easy again for a couple of weeks. At first, Jonathan was madder than ever -- I guess he had gotten used to us arguing with him. When we didn't, he went out of his way to test us. I thought we would have to put a lock on his door to make him obey the time-outs. But within two weeks Jonathan was hardly ever counted past two!"

Nancy and Steve are amazed at the transformation in Jonathan's behavior. "This is a kid who gets mad if you look at him cross-eyed," says Steve. "It really has been magic."

Help 'for "forgetful" Erin

For Fiona, a mother from Phoenix, the problem wasn't an explosive child but one who was habitually inattentive and disorganized. Fiona's nine-year-old, Erin, drove her mom crazy by forgetting to do her homework and by failing to get ready for school on time each morning. Fiona was run ragged because she had to help Erin with almost everything (or felt that she did).

"I'd pull out the spelling list and have to sit there pointing at each word while the dinner burned," recalls Fiona. "Or I'd hunt down the reading book or Erin's pencils, her eraser, markers, paper, and on and on. In the morning, I was practically dressing her myself. She couldn't pour a bowl of cereal without wandering off and goofing around. When the bus came, she was still in her pajamas, and her backpack was who knows where."

Fiona helped Erin become more responsible by finding ways to shift the responsibility for getting things done back to her daughter.

"I started out using a kitchen timer to keep Erin focused on her homework," says Fiona. "I made it like a game, to see if she could get all her supplies together her-self before the timer went off. We also began a chart, a daily calendar with stickers to add if she got her homework done and showed it to me before eight at night. If she got a certain number of stickers, she could pick from the 'date jar.' I put in slips of papers with ideas for activities for just the two of us, like 'make cookies' or 'take a walk to the park.'"

Another strategy that proved effective with Erin was forcing her to face the consequences of her mistakes. Once Erin forgot to change for school-and went to class in her pajamas. "I didn't do that again:" says Erin.

If you use charting, agree in advance how many successes it takes to win a prize (which might mean staying up late, having a special date with mom or dad, or another nonmaterial thing).

Alternatively, dock your child's allowance each time he neglects to do what's expected of him (for instance, withhold 25 cents each time you have to feed the cat because your son forgot). If fining your child doesn't work, dock another prized commodity, such as access to TV or to a favorite game.

CPRI Brake Shop

Putting The Brakes On Sensory Defensiveness

Sensory processing difficulties are thought to be due to a problem in sorting out incoming sensory information. At all times of the day our brains are aware of every touch and movement of our bodies, sounds, sights, and smells near us, and tastes in our mouths. That's a lot of information – so much so, in fact, we'd NEVER be able to get anything done if we were thinking about all of these things constantly! Fortunately most people have a 'brake in their brain' that helps them to ignore most things that their senses are telling them; only the things that are very important for them to know are let through.

Sometimes these brakes work TOO well, and so people end up seeking out strong sensory experiences to 'make up' for what they are missing – they have what's called a 'high threshold' for touch, sounds, sights, smells, tastes, movement, and touch. For these people, it takes a LOT before the sensory experience is 'too much' to handle, and they may not even notice things that they are supposed to notice (and other people DO notice). In individuals with sensory defensiveness, though, these brakes AREN'T working very well. This means that, on top of what they are supposed to be paying attention to, they have all these other things that they just can't seem to get out of their minds. We might feel all of our clothes tags, sock seams, or light breezes in the room. We might hear people whispering behind us along with everyone else talking together in one confusing noise. All of the colours and shapes whipping by, and all of the different perfumes and colognes that people are wearing are constantly grabbing our attention. Maybe it's the funny way tomatoes feel in your mouth, or how your stomach feels when you ride in a car.

In one way or another, people with sensory defensiveness have a LOT more things going on in their heads than other people do – they have a 'low' threshold for sensory information! **Other kids and adults would react THE EXACT SAME WAY AS WE DO if they were putting up with all that stuff, too;** the only difference is that they have a brake in their brains to keep all that stuff out of their thoughts. To make things worse, people with good brakes over their senses don't understand why we are making such a 'big deal' out of these things, and sometimes think we are making it up. Or else they don't realize how many things are too bright, too fast, too loud, too hard, or too strong for us and so we get in trouble when we **JUST CAN'T TAKE IT ANYMORE!!**

So give us a brake!



Avoidance. By recognizing how overloading certain situations can be for these kids, it is possible to **avoid the rages by avoiding the 'set-up'.** For

If a behavior is serious enough, a parent can go directly to time-out: "That's three and take five." If the child resists going into time-out, or if the infraction is severe, the penalty is increased: "Take five, and add five more for swearing."

Children, especially young ones, like to try to win time-limit contests. For example, you might say, "I see four things in the playroom that need cleaning up. I bet you can't find them 'and clean them up in 10 minutes!" Chances are, your five-year-old will say, "I bet I can!"

MARYBETH LAMBE, M.D., is a family physician and writer. She lives with her family on an organic dairy farm in Washington State.

Before you try 1-2-3 Magic

Think about your current approach to common obedience problems. How will the *1-2-3 Magic* approach work differently? How is your child likely to react – and how will you and your spouse handle it?


With your spouse, consider role-playing typical conflicts so that you both have practice with the method and can work better as a team.


Make sure you understand the difference between the techniques used to stop misbehavior (whining, nagging, and so on) and those used to start desired conduct (doing chores or homework.) *1-2-3 Magic* works best if you read the entire book or watch the entire video before implementing its ideas.


Remember: *1-2-3 Magic* is about building positive relationships with children.

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example, simply exposing a child with sound sensitivities to an echoing gymnasium full of yelling children and bouncing balls is unfair. In school, maybe another class can be substituted (at least when gym is indoors), or maybe the child only stays for part of the class until signs of overload begin to appear, or maybe earplugs are provided. In the home, maybe a different after-school club or quieter sport is chosen. **DON'T FORCE EYE CONTACT** – this creates more stimulation and may actually result in the child being LESS able to attend to you. Allow them to avoid this extra load, and find other ways of ensuring they have heard you (e.g. having them repeat the instructions).


 **Predictability.** Just knowing what's coming helps these kids to handle more stimulation before becoming overloaded; think about how different your reactions are to the sound of a door closing when YOU are closing it versus when you are sitting in a chair alone in the house. In both cases the sound is the same, but because in the second situation the sound is unexpected it automatically gets your attention more and 'feels' more threatening. It is helpful, therefore, to prepare these kids for environments you are about to enter: whether there will be a lot of people or not, whether they will be all sitting quietly or moving around doing independent work, etc. Doing so helps the child to accomplish the next strategy:


 **Mental Preparation.** Once you have an idea about what's coming, you can get ready for it (much like a swimmer takes a deep breath before diving so she can stay underwater longer). This might involve simply 'psyching' yourself up for the experience. It might involve developing contingency plans with other people (**"how am I going to know when I'm starting to lose it, and what will I say to cue others I've had enough"**). It might involve ways to make the situation more tolerable (e.g., **"as soon as I go into the room I'm going to find the most interesting thing to look at and just stare at that one thing"**). Finally, it might involve ways to 'make more room' in your head for what's coming (**"if I put my shoes on before I walk onto that concrete floor, the feel of the floor on my feet won't drive me nuts while I'm trying to put up with all of that noise"**).


 **Talking Through.** Developing 'self-talk' to reassure yourself (**"you can handle this; no big deal"**) helps – think of the television show "Fear Factor" and how contestants talk to themselves to get through something that is very overloading for THEM! You can also use 'self-talk' to make yourself laugh and deal with an uncomfortable situation that way (**"Ooo, ooo! Look at me, scared of a piece of hair touching my face! It must be Evil Hair, coming to get me!! What's it going to do – body-slam me?"**).


Oh no, the dreaded "just sit there" move.....ahhh!" 😊)

 **Counteraction.** There are certain things people can do, like rubbing an area of skin that was just attacked by the dreaded Evil Hair, that 'undoes' the bad feeling, or helps to reduce the overload. While this is a strategy used by the child with sensory sensitivities, it is important to recognize it to BE a strategy, and to allow it – don't misinterpret a child pushing your hand away and rubbing where you just touched, for example, as defiance or personal rejection. If the person you love most in the world were to run their fingernails down a blackboard, you would still shudder. This is no different.


 **Confrontation.** Sometimes people decide, **"Enough of this! I'm going to get over this!"** They then purposely face the very situation that is uncomfortable for them, in hopes that the discomfort will disappear. Whether this strategy works or not depends on how it is done; if you'd like to try it, it is best to do so under the guidance of a Psychologist who knows about behavioural treatments.

 **Use SAFE activities** (Sensory-motor, Appropriate, Fun, Easy); these are different games that provide for the sensory needs of people with sensory processing difficulties, and can be found in Carol Stock Kranowitz's book, "the Out-of-Sync Child Has Fun". Choose activities based on your child's interests, and what (s)he is showing you that (s)he needs. Allow the child to be in charge, and to do it his/her way as much as possible (stopping if it becomes apparent that the activity is actually distressing to the child and having the opposite intended effect). Use outdoor activities as much as possible. These activities when used properly create 'buffer room' in the brain – your child can now handle more stimulation before they will become overloaded! It is a good idea, then, to use these activities to help prepare for a high-sensory situation the child must participate in that is unavoidable. Take immediate advantage of this 'buffer room' you have created!

 **Develop a balanced 'sensory diet'.** This needs to be done with a registered and qualified Occupational Therapist.

 **Sometimes more is better.** People who get awakened easily by soft, irregular noises in their bedrooms can often sleep soundly when a constant, loud "white noise" is present. In a similar way, people with sensory sensitivities can tolerate certain sensations better at stronger levels. A light touch might send shivers down their spine, but a firm grasp feels good. An overpowering taste in his mouth (like

sucking on a sour candy) can help to 'drown' out other things in the classroom that are overloading and making it hard for him to concentrate on the lesson. Allowing for continual movement (e.g. a device to allow her to rock in a stationary desk chair, having something of an interesting texture to roll around between her fingers) can also improve focus tremendously.

 **Don't overflow the beaker!** When people are overloaded beyond their capacity to cope, things get ugly! This is like a beaker that is filled with too much water, and so starts to overflow and make a mess. The worse those brakes over your senses work, the more sensory information is hitting you all together and the fuller your beaker is. An overflowing beaker can cause someone to rage: it can also cause them to feel very, very anxious and even to have stomach-aches and headaches. If you are carrying a beaker filled with water almost to the brim, you have to be very careful with it so you don't spill any. It is the same with a person who is overloaded by their sensory information. Approach from the side rather than square-on, move a little bit slower around them, and warn them before you do anything. Crouch down to their level when speaking to them, and talk a little bit softer. Don't worry about what others might think – you know the situation, and they don't. Do what you need to do to not add even MORE stimulation to this poor overloaded brain!!

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What's new in Research

By
Brigitte Heddle

In "What is New in Research" I will this time take a look at 3 articles that all deal with AD/HD patients receiving neurofeedback training.

First, I will briefly explain what neurofeedback is. Neurofeedback allows a person to view their own brainwaves on a computer screen as they occur. Scientists have known for quite some time that the brain emits various brainwaves showing the electrical activity of the brain. There are different brainwaves for different brain activities, varying from being very focused and concentrated to daydreaming or at rest etc.

Neurofeedback practitioners feel that individuals with AD/HD can learn to produce brainwave patterns that are associated with a relaxed, alert and focused state and have them practice this skill extensively to the point where many of their AD/HD symptoms will diminish.

During a neurofeedback session the child has electrodes pasted to the head. Wires from the electrodes are connected to a device that amplifies the signal received from the brain by the electrodes. "The child sits in a

comfortable chair and can watch the signals on a computer monitor. The signals will show as a moving graph. The goal is for the child to learn to produce the type of brain wave activity that is associated with a focused and attentive state." * The proponents believe that the skills learned during the neurofeedback sessions are transferable to home and school. Strangely enough none of the articles describe exactly how the children learn to bring themselves to a relaxed state. It is only obvious that they learn to recognize not only what it feels like to be relaxed, but also what it looks like on the computer monitor

The first study was published in Neuroscience Letters, February 20th 2006 and written by J. Levesque, M. Beauregard and B. Mensour. In this study 20 children, who had AD/HD only and who did not receive any medications for their condition, received 40 neurofeedback training sessions and then had an fMRI (functional magnetic resonance imaging) scan to see how the neurofeedback training affected the brain. The results of this study suggest that neurofeedback training has the capacity to normalize the functioning of the part of the brain that deals with selective attention. This was seen as a reduction in inattention and impulsivity.

The next article that deals with the subject of neurofeedback and AD/HD is a summary of an article that was published also in Neuroscience Letters, Volume 394, Issue 3, February 20th, 2006, pages 216-221 (#11). The summary was published this year in Attention Research Update edited by David Rabiner of Duke University.

This article covers at least two studies on neurofeedback used to treat children with AD/HD.

Again the groups of children received 40-60 sessions of neurofeedback training and again in both studies the children seemed to improve from the treatment. In one study one group received medication and another received neurofeedback training and "both groups showed significant and comparable reductions in AD/HD symptoms according to their parents and teachers".

The author does however point out that the studies were not perfect, but had their limitations such as study methods and failure to sort out whether it was the actual neurofeedback or the extra therapist attention that brought about the improvement. The author does point out in defence of neurofeedback training that in the past therapy alone has not been the sole solution either.

However, in spite of the flaws in the various studies there is much evidence pointing to benefits of children with AD/HD receiving neurofeedback training.

David Rabiner concludes by saying that although additional studies are required to address the flaws in previous studies the current evidence of neurofeedback training's benefits should encourage the use of this method even now.

London Chapter
Tourette Syndrome Foundation of Canada
10th Annual Mini Golf Tournament

Seventeen people gathered at Windermere Golf Centre for our annual mini Golf Tournament.

Management lists 9 rules to be obeyed on the score card you get when you pay your fee. Imagine 7 kids with varying degrees of TS+ and moms and dads with their own “habits” trying to abide by these 9 course rules.

Rule # 1, “Please limit your playing to five players” got done-in first with a group of 4 and a group of 7. Rules 7 and 8, “Do not bang clubs on the concrete” and “Do not drag your club on the carpet” went next. Just had to be done because we were told not to. Rule #2 read “a ball near the edge of the playing area, green or obstruction may be placed 4 inches (a putter head away) in any direction” – *is over here ok?*

The last rule listed is “We reserve the right to refuse admittance or dismiss individuals from the course.” We’re so good at this that they didn’t even see us.

Scoring: 7 boys totaled 466, 4 girls totaled 296. Boys win with 66 over the girls with 74. This can’t mean boys are better. It must mean that more people on the team can beat fewer people on the other team.

Discussion before and after golf ranged from Botox treatments, taking showers and summer camp to mom being away for 2 weeks in Australia. Of the six families represented, the ages of those with TS ranged from 7 to 25 years. The kids held their own in the conversations and the adults learned a few new things.

As part of our participation in CPRI’s Tourette Syndrome video, we invited Andrew McKinlay to bring his camera and video us having fun. Andrew video-taped a lot of footage of kids with putters and some without.

And most important - the Ice Cream. After last year’s disappointment when the ice cream was too frozen to scoop, we were presented with choices galore. There were ten flavours to choose from - stuff like bubble gum, which someone must like or it wouldn’t be there, to vanilla, which at least one of our people chose. We could have 1 scoop or 2. We could have it in a cone or in a cup. We could even have 2 scoops of different flavours.

I had my favourite – mint chocolate chip. Two scoops in a cup with a spoon. If I put 2 scoops in a cone on a hot day I have to hurry and eat it fast to keep it from melting. With the ice cream in a cup, I can take my time and enjoy it.

Mark July 12, 2007 on your calendar so you don’t miss next year’s event.

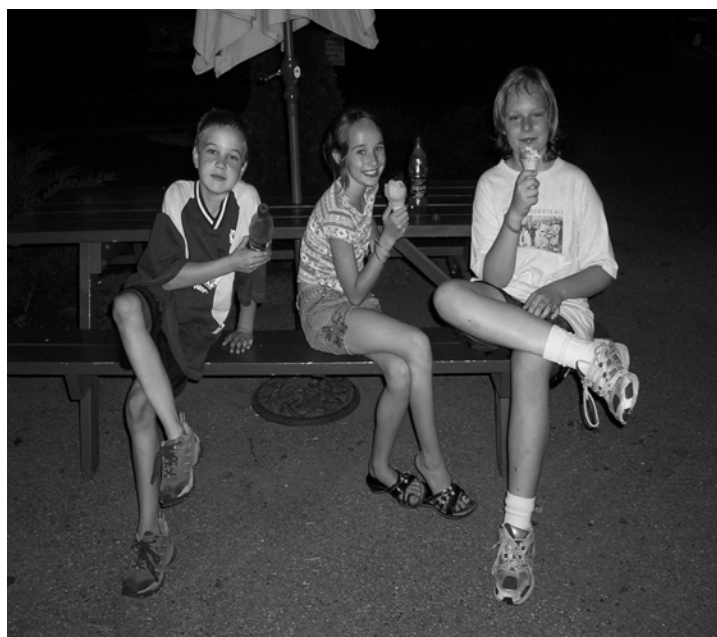
Ray



Ready, set, golf - Eight of our 17 players get ready to tee off.



Grown-ups socializing



Kids eating ice-cream

Tourettes in the News

Disc Jockey takes it outside

In the Toronto Star of July 7, 2006, Staff Reporter Christian Cotroneo writes about Jeff Goldberg, a young man who grew up with Tourettes, and who, now as an adult, helps TS children at Camp Winston four or five times a year.

Jeff never attended summer camp as a child because he was afraid of what might happen if he made his strange noises or tics in the night or if other kids would mock him.

In high school Jeff switched classes more than once because there were students in the class that would hassle him. Even after high school these same kids would give him a hard time whenever they saw him.

Today, Jeff runs his own DJ and event company and

is “delighted that his condition has been reined in by regular medication.” Jeff says “It’s the biggest warm-and-fuzzy to walk into camp, set up my equipment. I’m standing there playing music... and I got kids coming up to me saying ‘You have Tourette’s? Let’s talk about it.’ ”

The article promotes The Toronto Star Fresh Air Fund which supports children attending Camp Winston, among 98 other summer camps. The report states “Youngsters there (at Camp Winston) are among the 25,000 children the Fresh Air Fund will send to camp this summer, using a targeted \$575,000 in donations.

This article, printed in one of the country’s largest newspapers, gets Tourette Syndrome in front of the maximum number of people for a publication. Great coverage.

Please come out and help us run our next Charity Bingo Event on August 31, 2006, at Lucky Days Bingo, 530 First St. in London. It’s a great way to help raise money for the TSFC and our local London Chapter. For more information contact Linda Johnson: 519-649-5092

This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Ray Robertson. Anyone wishing to make any suggestions or comments about the content or if you would like to contribute an article for inclusion to the newsletter, please contact Gerard Johnson via email at:

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Visit your London Chapter Web Site at:

www.tourette-london.ca

"The information provided on a particular medication and/or treatment is individual. Please consult your physician for the best treatment for you. Opinions expressed in the material printed in this publication represent the opinions of the author and are not necessarily endorsed by the Foundation, nor does acceptance of advertising for products or services in any way constitute endorsement by the Foundation. Every effort has been made to locate the copyright owners of the material quoted in the text. Omissions brought to our attention will be credited in a subsequent printing. Grateful acknowledgement is made to those publishers/authors who asked that their ownership be noted."

