

President's Message

As I was looking through some of the material that collects itself on my desk, I came across this proclamation:

"Isn't it time people rediscovered their good manners and stopped staring?"

As a child I was often told "don't stare" as I imagine most of you were. My reaction usually was to keep staring but I tried not to let anyone see. After all, how could I learn if I didn't see?

We spend thousands of dollars to travel to far away places to see things that are new to us for the sole purpose of staring. Staring is natural. Seeing, in many instances, is our first step to understanding.

When I see a person who is, in some way different, I'm torn between the rule to "not stare" and the natural instinct to learn more. Without seeing more, I can't begin to learn more.

I may have missed the lesson about how we are to learn if we can't look, but if I have, so have thousands of others.

A couple of years ago I attended a workshop for TS kids and the first thing I noticed was a young man, about 17 years old, rhythmically moving his head from side to side while making loud sounds from his throat. What caught my attention was not so much this young man but a young girl in the next row who spent most of her time turned in her seat, staring at the young man and the rest of her time asking anyone around "Why does he do that?"

This to me was the ultimate in staring and I thought, "Where were her parents when they should have been teaching her not to stare?" I asked the person beside me why this kid was being so rude. The answer was that this young girl had a developmental disability.

This girl was doing what came naturally. She hadn't been influenced by society's rule of "don't stare." She wanted to learn more and this was the way she was doing it.

As for me, I also want to know why people around me are doing the things they are doing. So if you have a disability that catches my attention and I stare, it's because I want to learn more about your disability and our worlds will come closer together.

Ray Robertson
President, London Chapter

Best Hopes/Worst Fears by Kathie Snow

In TV-Land every week, risk-taking men and women tackle unpleasant, yucky, and sometimes dangerous situations on "Fear Factor." The pay-off? Self-esteem, pride, money, and more. In the Real World, ordinary men, women, boys, and girls also face difficult circumstances on a daily basis—taking a test at school, learning to drive (or holding your breath the first time your child drives alone), getting fired, getting hired, and a variety of other experiences that constitute being a human being in today's world.

In Disability World, however, things are very different. Many children and adults with developmental disabilities are "protected" by the Authorities (service providers, educators, and even parents) who are in control. And in these situations, people with disabilities are not allowed to take risks—not allowed to be in regular classrooms, live on their own, have Real Jobs, take care of themselves, and more. Fear—of failure, danger, or something else—puts the brakes on "risky" adventures.

Interestingly, it's often the *Authorities*—not the child or adult with a disability—who are fearful. But "fear" may not be the word that's used. Instead, the Authorities proclaim the person is unable to do [whatever], even though he's never had the opportunity to try! On the other hand, the justification for continued "protection" may be placed on the shoulders of "the community" or "the school" or some other entity which is judged "not ready" to include and support a child or adult with a disability.

Continued on Page 2

"In This Issue"

Disinhibited Thoughts #9	3
Camp Kennebec	4
CPRI Update	4
Annual Conference: 2005	4
Yard Sale	5
Waterloo Study	5
CPRI Brake Shop: Putting The Brakes On Behaviours	5
Book/Video Review	7

Support Meeting Report

*...continued from page 1
Best Hopes/Worst Fears*

The London Chapter of the TSFC hosts monthly support meetings from 7pm to 9pm on the second Thursday of each month, except for July and August, at:

Madame Vanier
Children's Services,
871 Trafalgar Street,
London, Ontario

At our last Parents Support Meeting we viewed the TSFC's newly released video/DVD, "Circle of Support" which is part of our Educators Resource Kit. This kit contains — "Circle of Support: A Practical Guide to Tourette Syndrome for Educators" VHS or DVD, an Interactive Workbook, a Facilitators Guide, Symptom Checklists, and "Understanding Tourette Syndrome: A Handbook for Educators, 2nd Edition!"

We are getting good turn outs each month at the Parents Support meeting and the Kids Klub is a great way for kids to meet and talk with other kids with TS. High School Exams are just wrapping up. Let us know how you and your children are dealing with this. Are there issues that need to be addressed or resolutions to a problem that you believe might help somebody else experiencing similar problems? Come and tell us about it!

Our next 4 meetings are:

Feb. 10/05
Mar. 10/05
April 14/05
May 12/05

Our Resource Library is available during our Support Meeting. The Kids Klub meets at the same location and time as the Parents Support Meeting. *(Please see our website www.tourette-london.ca for a list of rules for Kids Klub)*

***"Circle of Support: Educators Resource Kit"
is Available Now!***

We have copies in both VHS and DVD format available. The cost is only \$69 for non-members of the TSFC, and \$55 for members. Membership has its privileges! (Cash or Cheque only please) It is available through the London Chapter by calling Gerard Johnson at (519) 649-5092 or at the Parents Support meeting.

In other cases, a person with a disability may have once had a Real Job in the community or been included in school, but it didn't work out exactly as planned. When this occurs, the "failure" may be blamed on the person or the setting, the Authorities believe their fears were justified, and then decide, once and for all, that the person with a disability will never be successful in an inclusive setting, so no future opportunities are forthcoming.

In these situations, we employ a different set of rules for people with disabilities. In the Real World, would a person without a disability who has been fired from a job assume that she is not employable? No, she would most likely realize that, for whatever reasons, she and the job were not a good match, and she would seek a different job, knowing she will find the right jobs (like many others, she may have several different careers throughout her lifetime).

Fear—whether it's rational or irrational—can prevent us from moving forward into new opportunities. When it comes to the lives of individuals who have disabilities, this can result in segregation, lost opportunities, undereducation, underemployment, and other negative outcomes, which may be life-long.

Our efforts may also be self-sabotaged by the widely-held belief that we shouldn't hold onto "false hopes." Authorities of all types—including medical personnel—counsel parents and people with disabilities against having "false hopes." (What are they afraid of, on our behalf?) And what happens when, for example, parents embrace this way of thinking? They (and other Authorities) adopt a "realistic," narrow-minded way of thinking, which limits the child's opportunities for success. If Thomas Edison, Bill Gates, and others—both the famous and the ordinary—had been "realistic" and concerned with "false hopes," would they have taken the risks they took, tried and tried again, or done whatever it took to achieve their dreams? Shouldn't we be more concerned with the "false fears" that freeze us into immobility than "false hopes"?

What's lacking in so many scenarios involving people with disabilities are hope and optimism. We spend so much time being fearful, and so little time, if any, being hopeful and optimistic. It's as if "hope" and "disability" are mutually exclusive. But they aren't, and things don't have to be this way!

How to Reach Us	
<p>London Chapter Box 28013 London, Ontario N6H 5E1 519 457-4586 rayrobertson@hotmail.com www.tourette-london.ca</p>	<p>National Office 194 Jarvis Street Toronto, Ontario M5B 2B7 416 861-8398 1 800 361-3120 tsfc@tourette.ca www.tourette.ca</p>

TSFC London Chapter Administrative Committee	
President	Ray Robertson
Vice-president	Gerard Johnson
Secretary	Ray Robertson
Treasurer	Linda Johnson
Director at Large	Nadyne Gooding

One solution to this quagmire is the Best Hopes/Worst Fears exercise. More than a decade ago, the elementary school which my children later attended became an inclusive school via this strategy. The principal knew that educators had many fears. He also knew that until they addressed these fears, their efforts at inclusion might not succeed.

So here's what they did: over the course of several staff meetings, educators shared their Best Hopes and their Worst Fears with one another, writing them on flip chart paper which lined the walls of the room. In order for this method to bear fruit, staff members had to know they could speak honestly, that they wouldn't be chastised or ridiculed for their feelings. Through personal experiences, brainstorming, and open and respectful discussion, they learned that many of their fears were, indeed, "false fears." Then they openly and honestly talked about what it would take to make sure their Best Hopes came true and their Worst Fears didn't, and these were also listed on the flip chart paper and shared with all.

The Best Hopes/Worst Fears strategy can work for all of us. Any agency, organization, or school can use it in order to move to inclusion or other new ways of operating. An IEP, IHP, or other planning team can use it to ensure successful outcomes for a child or adult with a disability. And it's critically important that the person whose life is being discussed is an integral, active participant. We need to know what *her own* Best Hopes and Worst Fears are.

We can share our Best Hopes and Worst Fears when thinking about a person with a disability having a Real Job or living in the community. Then we can employ techniques to ensure the Best Hopes are realized and the Worst Fears never come true.

Parents can use this strategy within their families and drive the demons of hopelessness and "false fears" away, once and for all. Tackling our Best Hopes and Worst Fears can launch us into action. For example, if parents are reluctant to allow their child to be included in school or other activities because the child doesn't have sufficient oral communication to be easily understood by others, they might decide it's time for a communication device. That fear is now gone. If they're fearful their child may never be able to live on his own, they might decide to start teaching the child how to cook, shop, balance his checkbook, and other self-sufficiency skills.

When doing this exercise, you might discover that your Best Hopes and Worst Fears are flip sides of the same coin. One Best Hope, for example, might be that a person with a disability has friends, while one of the Worst Fears is that the person will be alone. When we get these out in the open, share them with others, and brainstorm solutions, we'll ensure positive outcomes.

In the end, employing the Best Hopes/Worst Fears activity is what most of us do for ourselves (often unconsciously) on a daily basis. When we walk out our doors every day, we assess risks, decide which are acceptable or unacceptable (and which are based on "false fears"), and then do whatever it takes to ensure the risks we take result in a benefit.

Isn't it time to ensure people with disabilities have these same opportunities? Shouldn't they also be able to enjoy the dignity of risk, the power of learning from experience, and the benefits that come from living a self-directed life?

"Used with permission of the author."

© 2005 Kathie Snow. If you would like a handout version (PDF) of this article, please send your request, along with the title of the article ("Best Hopes/Worst Fears") to: kathie@disabilityisnatural.com. You may share and/or distribute the PDF version of the article to others (non-commercial use only). As a courtesy, please let me know how/when you use it. Please do not violate copyright laws: request permission before reprinting in publications or on websites. "For permission to reproduce, contact kathie@disabilityisnatural.com."

Disinhibited Thoughts #9

Growing up, I wasn't by any stretch of the imagination what anyone would have considered a "catch" romantically speaking. Or maybe I simply decided I wasn't, and this belief in itself made that true.....

Granted, despite my for-the-most-part successful efforts to suppress tics, as a teen I was still emotionally volatile, unstable, pretty obtuse socially and, for many years, rather fat. I'm betting that none of these qualities rank particularly high on Chatelaine's "Recipe For A Hunk" list.

Yet losing over 70 pounds and working out regularly seemed to make little difference. Gradually becoming more socially aware through explicit skills training seemed to make little difference. Doing post-graduate work with a good career ahead seemed to make little difference. And, perhaps most confusing and frustrating of all for me, treating romantic interests like royalty seemed only to encourage them to run faster. It all seemed so backwards: I showed every consideration possible. I drowned them in affection. I doted on every word, and worshiped the ground they walked on. And nothing. Was I that repugnant? Was TS such a hideous quality that, even when hidden, it negated any positives I could possibly ever muster?

I certainly believed so. Such a fate angered me. I looked for stones I had not yet unturned to beat it. I sunk into depressions over it. Eventually there was nothing left to do but accept it. This is who I was, it was not what this world desired, and that was ok. I'd get by. So I stopped trying so hard with women, and refocused my energies into my own pursuits.

Bingo. Imagine my disbelief as my dating fortunes then began to grow, and continue to do so. The final irony was of course that I hardly suppressed anymore: certainly when I do suppress now it is with dubious success (those muscles have atrophied from disuse) and is borne out of respect for a situation rather than embarrassment. Hence my ticking has become unapologetic and outright bizarre. Huh? Were all those Cro-Magnon men right that asserted the less YOU cared, the more the WOMEN did??

Of course not. Obviously you have to care about the person you date. But you have to show that you care about *yourself* too. That had been the missing and most crucial piece up until then. I

recently approached a fellow graduate student to ask her how I've changed over the four years she's known me (a time period which has seen me go from a forced dating abstinence to multiple opportunities) – without hesitation she replied I was now much more self-assured and, as a result, more laid-back and positive about myself. So maybe the TS DID play a role in my dating difficulties, but that role was to alter my self-view, and the attitude I exuded. It was never about the tics themselves.

Attitude oozes from our every pore and gives people information on how to treat us. It is in your gaze, which may or may not falter when you tic. It is in your shoulders and stride, which may or may not be proud. It is in your priorities, which may or may not send the message "you are important to me but I will not always put you first because I am important too". It is in your dating reactions that may or may not say, "I think you are great and hope you like being with me, but it is not something on which I hinge my belief in my own worth". I have learned that believing I deserve ridicule causes me to be hyper vigilant of reactions, and even, in retrospect, to disbelieve individuals that claimed to have an interest in me. I have also learned that believing any cruel reactions say more about the reactor than about myself causes my awareness of many reactions to disappear. It has also led to a number of people approaching me with a whole new flavour of reaction – demonstrating admiration for my choice to be myself, and curious questioning.

Belief in yourself is the ultimate aphrodisiac. Pit it against TS – even tics as severe as mine – and it will trump the disorder without even breathing hard.

Until next time, my friends!
B. Duncan McKinlay, M.A.Sc.
Ph.D. Candidate, University of Waterloo,
Visit "Life's a Twitch!" at www.lifesatwitch.com

September 2000

Camp Kennebec

Camp Kennebec has sent us a brochure with information about their summer program.

Their brochure advertises "An integrated summer residence camp for children with various learning disabilities, autism and other social and behavioural difficulties.

Camp Kennebec is located on Bull Lake between Ottawa, Kingston and Toronto. They accommodate children from age 6, Counselor's in Training for ages 15 - 17 and have an intern program for ages 16-24.

For more information about their activities go to their web site at www.campkennebec.com.

A Confidence Test

When you ask your computer to check the spelling of your file and the computer finds an error and asks if you want only this occurrence of the spelling error corrected or if you want all occurrences of the spelling error corrected, what is your reply?

CPRI Update

The CPRI Brake Shop for Tourette Syndrome & Associated Disorders "for when it's hard to stop..."

It is only our seventh month of operation, and yet as of January 19th the Brake Shop has already accepted 77 referrals into our program! This speaks to the dire need for a clinic such as this in South-Western Ontario, given that by definition children and youth accepted into our service are experiencing severe difficulties and have already accessed many other services in their local community. Our team is feeling increasingly trained and very enthusiastic, and many of our services have now been launched. While overall we are pleased with how things are progressing, we regard this first year as a time to catch wrinkles in our procedures and services. Since we intend to work hard honing our offerings, any feedback as to how we're doing is most welcome and encouraged!

With regards to our clinical services, most of our referred families have either already come in for their intake assessment and to develop a plan of care, or are booked to come in. In addition to myself, our team's occupational therapist, social worker, physicians, and community behavioural intervention consultants (CBIC's) are busy seeing many of these clients for consultations, assessment, and intervention. A first pilot of our self-management group was completed just before the holidays, with plans to begin with a second set of clients in February. We are now also well into our first run of the social communications group.

In terms of education, we are pleased to report that between classroom in-services, school staff presentations, and training mental health professionals we have now touched over 2100 audience members, with many more presentations booked well into 2005! Our inaugural "Leaky Brakes 101" course is half over (three sessions down, three to go) and will continue until April 2005. In the future we expect to shorten the interval between sessions so that we can offer the course more frequently in the year.

That's all for now -- remember that it is up to all of us to help "give these kids a brake"!

Duncan

Annual Conference 2005

Just to let everyone know, the next Annual National Conference for the TSFC will be in Montreal, on October 20 - 22, 2005. So book that weekend now so you aren't disappointed later!

Yard Sale

Just a reminder folks that Saturday, June 4, 2005, has been set for our 3rd fund raising Yard Sale. Money raised from this event will go towards Chapter operating expenses.

Keep us in mind between now and June when you have something you want to throw away – it might have some value at our Yard Sale. We will begin collecting items in April.

If you can help out on the day of the sale, let us know. All hands will be welcome. We have a possible location (the home of one of our volunteers) but if you have a better one, we would like to hear from you. Also, we could use some space to store items prior to the sale date and help with moving things from place to place.

Or just drop in on the day of the sale and spend some cash.

**Note: If you borrowed any books or videos please remember to return them so others can enjoy their benefits. If you are having trouble getting to the monthly meeting but have borrowed material please drop the material off at Madam Vanier Children's Services and have it labeled for the Tourette Syndrome Foundation of Canada.*

Waterloo Study

Your Participation is Needed!

- Do you have Tourette Syndrome?
- Do you have a sibling with Tourette Syndrome?
- Are you the parent of a child with Tourette Syndrome?

Please take part in a web-based study on family and sibling relationships in families with a child with Tourette Syndrome. This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo, Waterloo, Ontario, Canada.

Any English speaking person from any where in the world can take part in this study.

Your participation will contribute to a research study as well as the Tourette Syndrome society. Feel free to email your questions to: mmalekit@watarts.uwaterloo.ca

Please visit <http://mrosslab1.uwaterloo.ca/ts/>
You can make a difference

University of Waterloo
Department of Psychology

CPRI Brake Shop:

Putting The Brakes On Behaviours



You may have heard of the disorder called "Oppositional Defiant Disorder" (ODD) and wondered what it means. Join the club! To hear the 'symptoms' of ODD, the diagnosis seems to be merely a description of bad behaviour – the criteria doesn't really give you any ideas as to where this comes from, and there is no research suggesting genetic or neurological causes for this disorder. That doesn't leave us with a lot of ideas for dealing with those behaviours, and usually the parents or professionals are left with thinking of ways to motivate the child into behaving. There IS, however, increasing evidence that oppositional and defiant behaviour does not occur all by itself. In other words, the research that says, "children don't simply choose to be bad" is growing. Many times children have other disorders, and these symptoms are either being mistaken for wilfulness or "brattiness", or are setting the stage for these behaviours to appear.

Many of these disorders can be thought of as being problems with being able to stop oneself – for example, stopping one's movements and sounds (TS), stopping one's impulses (ADHD), or stopping one's thoughts (OCD). Being able to stop what YOU want to do when someone else demands that you do something else, without getting angry about it, requires good brakes too – given all of the "leaky brakes" that these children may already have, maybe THESE brakes are leaky too! If that's true, then we shouldn't be looking at these kids as WANTING to be disobedient. Instead, we should be interpreting their problems as a natural reaction to their struggles to cope with "leaky brakes".

So let's give 'em a brake!




Many parents indicate that their child seems to have an "automatic no" response – even when asked to prepare for an activity (s)he enjoys! Don't react as if the "no" is personal (i.e. with emotion) or an invitation for a power struggle...because often it isn't! Many times an "immediate no" can be changed to agreement if the child is given some time to process the sudden change in plans. Instead of 'taking the bait', then, simply come up with new language together (e.g., "I need a second") for the child to communicate the difficulty that (s)he's having in putting on the brakes and changing direction. Also, anticipate and prepare for the extra time that will be required for these children to adjust to the new direction.





Another technique to try for reducing power struggles is **to quote the rule rather than your authority** in the situation as a parent. For example, rather than saying, "You are going to finish your homework before watching TV because I'm your mother and I said so", you may wish to try, "the rule in this house is that everyone must do their work before they get to have fun".





Using the word, "**Stop!**" rather than "**No!**" has been reported by some parents to be useful in averting oppositional reactions.

 **Provide choice options:** “WHEN you are doing your homework, do you want to do it at the kitchen table, or in your room? With the pen or the pencil? On the computer or on paper?” Emphasize the child’s control in the situation (i.e. it is entirely up to him/her what to do, but the consequences will therefore be of his/her own choosing).

 It is recommended that the school and home **both involve the child in the development of rules** as this will help to decrease power struggles. As long as adults in the child’s life unilaterally lay down rules, defiant rejection of those rules is a way for the child to assert him/herself. Once rules are created together, though, this means that a failure of the rule is also now a personal failure on the part of the child. Hence the child will become more implicitly motivated to invest in the success of those rules. This is also a way to help the child feel more in control and less ‘acted upon’, which will have positive ramifications for self-esteem.

 Similarly, it is vital for the child to understand **exactly why certain rules and strategies are in place:** their existence alone is not sufficient. If the child assumes that certain exercises are simply additional burdens adults have inflicted upon him/her, (s)he will rebel against them. If, however, WHY and HOW these strategies will better his/her life is explained, (e.g. emphasizing how these rules make things “fair”), they may be adopted more quickly and easily.









 This is a strategy for the child that has developed an arsenal of techniques to remove him/herself from the situation when work becomes difficult. Before attributing these behaviours as apathy, indifference, or a power struggle, the surfacing of these behaviours should be considered to be a **potential signal that (s)he requires additional assistance** in some regard. It is not a coincidence that psychologists often see the most avoidance behaviours during tasks in which the child’s abilities are weakest.


 Given possible self-esteem issues, it will be important to stress to the child that **it is the NON-COMPLIANT BEHAVIOUR that is unacceptable, and not HIM/HER.** Furthermore it can be emphasized that it is the choices (s)he makes that determine whether (s)he receives rewards or punishments, and not whether his/her teacher, peers, or parents like him/her or not.


Once any ‘leaky brake’ disorders have been properly identified and accommodated for, if the child does not follow through with expectations it is important to use (and you have now “bought the right” to use) good behavioural modification techniques in dealing with the situation. Not because ODD is necessarily due to “bad parenting” or “spoiled children”...but because these things, if they exist, will make any problems even worse!


“B-Mod” is always a good thing to have in place with any child — it just isn’t the solution to every problem and certainly doesn’t teach the skills necessary when a person has “leaky brakes”. For that reason, **before B-Mod is used it needs to be overlaid with**



any necessary accommodations for existing disorder(s). That way, we are more confident that any non-compliance is about lack of motivation (which punishment CAN influence) and not a skill deficit (which punishment can do absolutely NOTHING for).


-  Use the following techniques when issuing commands:
 -  be physically near the child; minimize other distractions that might be present
 -  issue command only after obtaining eye contact with the individual
 -  use a calm but firm voice
 -  use direct statements (“put the toys away now”) rather than questions (“will you put the toys away now?”)
 -  give only one command at a time
 -  be brief and to the point
 -  look at (i.e. “stare”) at the child for 20-30 seconds after the command is issued; this communicates that you mean business and expect compliance. It also gives the individual a chance to re-evaluate what may be an initial, impulsive reaction without applying pressures that increase stress and make brakes even leakier (e.g. raised voice, threats). Do not repeat the command until after this period of time has elapsed. Do not stare angrily – simply maintain eye contact and a serious expression


 If the command is not obeyed, the situation should be **discussed** as soon after the child has followed through with expectations and the **tension has subsided**. Be careful not to discuss things while/if the child is still overloaded – see “Putting The Brakes On Rage”.


 The initial part of the conversation should be designed to **determine if the child knows what the expectations are** and how to meet these expectations. If the problem is a result of a lack of knowledge or skills, (s)he will need to be reminded, cued, or taught what to do.


 If (s)he does know what to do and is being “non-compliant”, then in a calm, but firm voice, (s)he should be re-told the expectations. If the child wishes to argue, it is best to continue, in a calm, firm voice, to **outline the choices, with the consequences for each choice clearly explained** to him/her. It is best to make these “natural” consequences. For example,


-  if (s)he damages property then (s)he should provide some kind of restitution
-  if (s)he hasn’t finished what (s)he has been asked to do then (s)he cannot have his/her snack yet


 If the child continues to be uncooperative, **the consequences should always be followed through on**. It is very important to not concede to his/her wishes once an expectation has been made, as doing so rewards the child for being oppositional and ensures that (s)he will continue to resist others' expectations in the future when they don't correspond to his/her own.


 It will be important to ensure that consequences are **consistent, immediate, and sufficiently aversive**:


 if, for example, the child recognizes that (s)he can get away with a certain undesirable behaviour **5** times before getting into trouble, rather than learning to not engage in that behaviour (s)he will instead learn to only engage in it up to **4** times. This scenario can be avoided by teaching the child that a particular behaviour will lead to a particular consequence every time; there are no 'build ups'.

 likewise, if engaging in certain undesirable behaviours results in successfully avoiding whatever it is (s)he does not want to do, the child will learn to do that behaviour more and more and for greater and greater amounts of time to get what (s)he wants. Therefore consequences must, as a component, include completing whatever task it was that was being avoided in the first place.

 Finally, **be careful that punishments**, although intended to be negative, **do not contain positive elements**. For example, if a child very much wants more attention from you, a punishment that involves drawing a considerable amount of your time and/or attention may in fact increase rather than decrease the undesirable behaviour.

 The **child's own power of choice should always be emphasized**; rather than being a power struggle between adult and child, this is a situation where the child is master of his/her own destiny.

 Sometimes it can be helpful to **switch tasks momentarily** before going back to the original expectation.

 Some children benefit from **social skills training** that incorporates verbal mediation strategies, problem solving, perspective-taking, and role-playing. This can help in learning appropriate social behaviours, and in understanding what effect his/her behaviour has on other people.

An initial reaction from the child to behaviour modification can be expected – for a time the behaviour will get worse. This is ESPECIALLY true if the child has grown accustomed to getting his/her own way in the past. The child will see these new strategies as beatable too, and so will resist these new standards expecting that you will eventually cave in. Rather than being a step backwards, **this increase in bad behaviour (called an "extinction burst") is in fact progress and the first step towards better behaviour**. The key is to stand firm while the

child tests the new status quo: once the child realizes you aren't going to budge, (s)he will adopt the new rules. Despite how heart-rending this process may feel, it is imperative that neither home nor school drop these new strategies during this new learning time. To do so would tell the child nothing has changed except that (s)he now needs to act out to a greater extent to get what (s)he wants.....making the problems that much worse!!!

© 2004, Dr. B. Duncan McKinlay, Psychologist



Book/Video Review

Quit it

By: Marcia Byalick

Published in 2002

Hardcover

171 pages

Delacorte Press

"Quit It" is a fictional story of a 12 year old girl's first year dealing with TS. Carrie goes through a 3 month period of visiting doctors to finally come up with a "french" word for what's wrong with her. School starts in a couple of weeks and Carrie is worried about how she will deal with school and Tourette syndrome.

The story describes many of the problems school age children have dealing with their peers and teachers and provides insight into Carrie's feelings as she copes - day by day. Remarkably, Carrie's parents, while understanding the diagnosis of TS, don't know how to interact with Carrie.

Breakthroughs are made with peers and staff at her school and most importantly, with her mother and father and her older sister. The story ends with Carrie continuing to deal with symptoms that affect her "quality of life" but with those around her understanding more about what she is going through. This makes Carrie's life infinitely better.

All possible symptoms of TS are never contained within one person. This book is a very plausible story of one case of Tourette syndrome and contains no inaccuracies. Provided you accept that your child may have TS and exhibit none of Carrie's symptoms, I recommend this book as well worth reading.

reviewed by Ray Robertson



Tourette Syndrome Foundation of Canada

London Chapter



This newsletter was produced for the London Chapter of the Tourette Syndrome Foundation of Canada by Gerard Johnson. 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 via email at: gerard.johnson@sympatico.ca

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."