



Tourette Syndrome Foundation of Canada

London Chapter

Newsletter

May 2005

Why Do We Apologize?

Revolutionary Common Sense by Kathie Snow

Whether we realize it or not, we do a lot of apologizing on behalf of people with disabilities, and many individuals who have disabilities apologize for themselves on a regular basis. Whether these apologies come in the form of excuses, explanations, or regret, they're unnecessary, at best, and harmful, at worst.

During the first few times my friend, Tom, and I were together, he routinely said, "I'm sorry," numerous times. When we left a room, I held the door for him. As he wheeled through, he looked up and said, "I'm sorry." When he dropped something on the floor and I retrieved it for him, he threw out another, "I'm sorry."

Why did he do this? After I got to know him a little better, I asked him, and his response stunned me! "Ever since I was little," he said, "I've needed a lot of help from other people. No one ever said anything to me about this, but I always felt that my needing help was a bother to others-like when they had to stop what they were doing to help me. I apologize because I'm sorry I'm a burden to other people."

I was astounded! I ranted, with great love and emotion, that a friend helping a friend is never a bother or a burden! He mumbled something indistinct and I raved on. I told him that when I had my arms full of packages and someone (even a stranger) opened a door for me, I didn't apologize or think of myself as a bother. I simply said, "Thank you."

Tom had never thought of things that way. For whatever reasons, his vision was skewed. Until our conversation, I don't think Tom had ever considered that the help he received from friends-or even strangers-was no different than the informal assistance people *without* disabilities give to each other day in and day out. After our conversation, Tom agreed he would work hard to replace "I'm sorry" with "Thank you," when someone gives him a hand with something.

Many parents also apologize for their kids with disabilities, although they may not use the words, "I'm sorry" or "I apologize." For example, when four-year-old Micah, who has autism, goes ballistic in the grocery store check out lane, his mom, Marie, turns to the nearby gawkers and says, "He has autism," as a way to explain her son's behavior. (Many parents have admitted, however, that they're really trying to protect their own images, by letting others know what their children's behavior was not the result of "bad parenting.")

When I speak about this subject at conferences, I ask the following: "Has anyone *ever* seen a four-year-old child who *doesn't* have a disability label go ballistic in the grocery store check out lane?" Most people laugh and agree they have. I then ask if the mother "explains" the child's behavior by announcing to the gawkers, "He takes after his father!" In general, this doesn't happen. Why? *Because it's nobody's business!* Parents of kids who *don't* have disabilities don't feel compelled to explain about their children's looks, behavior, or anything else. They don't feel the need to apologize. The same can and should be true for parents of children who have disability labels.

But some parents disagree with this. They feel it's beneficial to educate grocery store patrons (or others) about their child's condition. I agree that, if one has the time and the energy, it can be helpful to educate others about the "condition," but never about the child! What must it make a child feel like when his mother talks about him like he's not there? And how many times has this already occurred in his life? *We must protect a child's privacy and dignity.*

So if the child is not present, and *if* the parent has the time and energy to do a mini-lecture, she can go for it. When this is not possible, or if this isn't something a parent wants to do, she can use humor to elevate herself and her child above a sticky situation. (See the "Humor to the Rescue" article.)

Professionals apologize in various ways, as well, resulting in unintended and negative consequences. For example, when an employment counselor (Fred) is attempting to secure a job for a Matt (a person with a disability), he may inadvertently sabotage his efforts with a word here, a tone of voice there, or body language that is apologetic in nature. "Yes, Matt can do [this or that], but no, *[big, bearing sigh accompanied by shoulder shrug and shaking of head]* he's still struggling with [whatever]."

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President's Message

Inside this newsletter is an article describing a TS research project being carried out in "Our Own London" by Dr. Rob Nicolson. Over the past 10 or so years there has been an increasing flurry of research, most of it funded by the Tourette Syndrome Association of America. Although I understand a little of what I read regarding these research projects, there is much more that I don't understand. Thankfully, most project summaries are written in a way that I can see where they are leading.

But what is the ultimate goal of TS research? And, whose goal is it? Is the goal to find a cure, and if so, a cure for whom and a cure for what?

My experience has been that concern for a cure is one of the first things that come to mind after a diagnosis. During the next steps of accommodation and acceptance and the investigation of medications and coping strategies, the concern for a cure gets put aside. Later, when time allows, thoughts return to a cure but the context has changed.

To me, hearing of someone not wanting a cure was a novel idea. An 18 year old girl was saying that TS was so much a part of who she was, she just wouldn't be herself anymore without her TS.

Since that first time, I have heard many stories, both first hand and passed on, from books and from the media, that go beyond "TS is part of who I am" and tell about valuing TS. Some simply value that TS makes them unique. Stories are told in phrases like "my Tourettes is a big part of me. It's a big part of my life" and "even the bad part is such a big part of who I am." One especially unique story is told as "when no-one can see, it's so great to let my Tourettes out. Someone who doesn't have TS will never enjoy that feeling."

Recently I came across a magazine article that suggested that people with disabilities are not broken and they don't need to be fixed. "The problem never has been the disability; the problem is (and has always been) society's beliefs about disability." And if we seek a cure for our children are we implying that they are in some way defective?

I went to a friend with TS for some insight. I asked two very specific questions:

First - "If you could personally direct TS research into an area that would help you what would that research be?" The response was not at all surprising.

"I honestly can't think of anything." A further elaboration implied that acceptance of the disorder and experiences to date made him confident that he could handle anything that was in store in the future and concluded with "I believe in my own ability to endure and improve anything in the future that life has to throw at me."

Second - If you could personally direct TS research into an area that would help others what would that research be?

"Anything ... that provides ways for families to immediately improve their quality of life." It is imperative that we have a delivery system that gets new information into the hands of the people who need it and in a form that can be understood and readily applied.

Research will continue, if only because the Mountain is there. Research will keep providing pieces to the puzzle. Perhaps some day, even though we may not accept a cure, we may be ready to accept that our children could be free of TS.

But the cost will be the loss of a small piece of the diversity that makes each of us so unique.

Ray Robertson
President, London Chapter

TSFC London Chapter Administrative Committee

President Ray Robertson
Vice-president Gerard Johnson
Secretary Ray Robertson
Treasurer Linda Johnson
Director at Large Nadyne Gooding

Miniature Golf - Family Fun Night Thursday, July 14, 2005

Everyone is welcome to come out and join us for our annual evening of miniature golf, ice cream and relaxed chit chat. It's a good chance for socializing for the kids and adults! It's all happening on Thursday, July 14, 2005 at the Windermere Golf & Learning Centre, 1324 Adelaide St. N. (Northeast corner of Windermere Rd. and Adelaide St.) See you there!



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Disinhibited Thoughts #10

"I still cringe every time I read about how your family didn't understand you. It sounds like they were awful....."

My sister wrote this to me in an email recently, shortly after I proudly circulated an article chronicling my difficult youth. I am ecstatic that Heather and I have now, after so many wasted years, gained a measure of comfort with one another -- enough to trust her brother with something so sensitive. Her comment made me pause and consider something I have until now been rather unmindful of: the impact of diagnosis on parents, families and even many teachers can be considerable. Many feel crippled with guilt once they learn that this child or student they have been disciplining for inappropriateness has had a disorder all along. It further occurred to me that I should write something to alleviate that guilt, for it is undeserved.

I can well understand why my sister cringes.....in each of my presentations and interviews I tend to divulge at least some of the wretched private depths I inhabited for many years. My logic is that if I want people who are lost in Tourettic turmoil to believe in their own ability to eventually prevail then it is important to establish that others have done exactly that. After all, it is easy enough for someone who has not been scarred by such unremitting dejection and rejection to smugly suggest you merely "buck up". Easy enough, but incredibly minimizing without any spoken appreciation of what you've experienced.

While I WAS miserable in my youth, and so this work I do provides tremendous personal validation to the emotions I endured, quite honestly I do often cringe myself at those articles. This is because I do not in any way hold my family responsible for their unaware reactions to my TS. It is absurd to have expected them to understand and accommodate for neurology I myself didn't comprehend, and that had gone unrecognized by any professionals they'd spoken to about me (something I have only just learned that they did). If we are to begin assigning blame then I'd better take my OWN place in line as well. By not trusting my family with my "big secret" I decided for them that they wouldn't understand and set the stage myself for further hurt.

To both my family and others burdened with remorse I offer this: what truly marks your calibre is how you've reacted SINCE you've known what was going on, not how you acted BEFORE. You've attended presentations. You've read literature. You've watched videos. You've reached out enthusiastically and supported in all the ways you did not know how to before but wanted to. It is on THAT plane you deserve to be judged.

Just as families like mine should not feel culpable for pre-diagnosis actions, TS'ers like myself should also not cast blame for pre-diagnosis actions. It is very important that we learn to forgive the world for its inadvertent treatment of us, which is a topic I'll broach in a couple of months.

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

December, 2000

New Ombudsman makes families top priority

TORONTO – Andre Marin, the new Ombudsman of Ontario, is making families affected by severe disabilities priority number one. Despite the Ministry of Children and Youth Services' pledge that no parent should have to give up custody of their child to access special needs supports, Marin says the Office has received complaints to the contrary.

Members of our own TS community are among those complaints after all efforts by the Foundation to assist these families were exhausted.

Marin, who took office April 1, 2005, is launching a special investigation into whether or not parents are being forced to put these children into the custody of Children's Aid Societies because they aren't able to get the care and attention needed otherwise.

"My investigation will determine whether parents have been placed in the unconscionable situation of choosing between retaining their parental rights and obtaining necessary residential care for their children with severe disabilities," said Marin. I intend to use the extensive powers of my office in this first investigation by the newly created special Ombudsman response team."

Marin is calling upon Ontario residents, specifically families who have had similar experiences, to come forward with any information that could help the investigation. If you would like to participate, or know of a family in your community that would be interested in this investigation you can reach the Ombudsman's office at 1-800-263-1830 or online at www.ombudsman.on.ca.

Learning Disabilities Association London Region

Tutoring for ages 8 - 16

Support group for adults with
Attention Deficit Disorder

Lending library

On the web at www.ldao.ca
Or call 519 438-6213

Continued from page 1: Why Do We Apologize

Instead of using words and body language that make Matt look pitiful or unworthy (and which slam the door on his chances at the job), Fred can reframe and rephrase his message to something like, "Yes, Matt can do [this or that] and [*proud look and enthusiastic tone of voice*] he's getting closer to being able to [do whatever]." Some may think this difference to be so slight that it wouldn't matter. But a seemingly minor change in communication (words, tone of voice, body language) can present an entirely different picture.

One of my son's elementary teachers had great skill with language. Some teachers describe children who haven't yet mastered reading as "non-readers," "slow readers," or something similar. Mrs. Myers described them as "emerging readers." The skills were *emerging!* Is the glass half-empty or half-full?

After I spoke on this subject at a recent workshop, David, the father of a four-year-old daughter who had Down syndrome approached me. "I have a confession to make," he said. "People come up to my daughter and me in grocery stores, malls, and other places and say, 'Oh, your daughter is so cute!' And she really is—we're so proud of her. But when people say that, I answer, 'Thanks, but she has Down syndrome.' *I don't know why I do that!* I guess I'm apologizing for her disability and I shouldn't!"

David was quiet and thoughtful for a moment, then added, "I guess it wouldn't be much different than if someone told me I really had a great mom, and I said, 'Yeah, but she has a lot of flatulence!' That wouldn't be right, so what I've been doing to my precious daughter isn't right either! I'm not going to do it anymore. When someone says my daughter is cute, I'll just proudly say, 'Thank you!' No more apologizing!"

With a furrowed brow, David then expressed concern about what affect his past actions and words might have on his daughter. My suggestion was to talk to her about it, apologize (this is the time when an apology *is* appropriate), and assure her it won't happen again. I feel it's important to own up to our errors. Others will forgive us and help us do better.

If we spend time thinking about our words and actions, we may discover a variety of ways in which we apologize or make excuses for people with disabilities—even without saying "I apologize" or "I'm sorry." If we're determined, we can find ways to reframe our communication to eliminate apologist explanations and ensure we're promoting positive images. It's important to do this if we're going to change societal attitudes. It's even more important, however, for the self-esteem of the person with a disability label. Seeing people with disabilities as individuals who are our equals, and who are entitled to common respect and dignity means never having to say, "I'm sorry."

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Yard Sale

We had our annual Yard/Garage Sale at Ray Robertson's house on Sat. May 28/05. It was an overcast day with rain threatening most of the time, so it was not as well attended as in previous years. We'll give you an update on how we did next Newsletter.

TSFC Annual Conference 2005

The next Annual National Conference for the TSFC will be at the Delta Centreville, Montreal, Quebec, on October 20 - 22, 2005. A Preliminary Program And Registration Information Will Be Posted on the TSFC's web site. You can expect the usual world class speakers, an educators day, and programs for children, youth and adults. Make your plans for that weekend now so you aren't disappointed later. See you in Montreal!

Canada Continues to be Part of TS Research

Dr. Rob Nicolson is best known in the London TS community for his work with TS children at CPRI, however, Dr Nicolson is also working to further advance the knowledge of TS through research being carried out in conjunction with the University of Western Ontario.

Dr. Nicolson is in his second year of a project titled "Brain Magnetic Resonance Imaging and Magnetic Resonance Spectroscopy in Tourette Syndrome" assisted by research grants from the Tourette Syndrome Association, Inc of the USA.

The previous year's study using magnetic resonance spectroscopy (MRS) suggested an increase in specific activity in 2 areas of the brain. In this years study, Dr. Nicolson hopes to confirm and extend these findings by the use of magnetic resonance imaging (MRI) and MRS. Children and adolescents with Tourette Syndrome and a control group of children without tics or other major psychiatric illness are part of the study.

It is expected that the results from these studies will further advance the knowledge of the neurobiological basis of Tourette Syndrome and may ultimately be important in determining more effective treatments for tics.

The TSA, in 2004-2005, funded 14 research programs in the fields of immunology, neuroimaging, brain chemistry, genetics and clinical drug trials with a total of almost \$875,000.



"Fortunately, most counting obsessions end in odd numbers.
How else would we get the light turned off."



Book/Video Review



Tictionary

235 pages by Becky Ottinger

Published in 2003 by Autism Asperger Publishing Co.

As the name implies "Tictionary" is a reference book. The index includes over 400 entries such as Anger, Resource Room, Internal Tics, Clothing, etc. The author is the mother of Joshua, a boy with TS. She uses her and Joshua's experiences to help define a topic and goes on to provide advice and information about how to cope. The material isn't limited to personal experiences.

Becky, as a teacher, watched children with TS in her classroom and as a volunteer with a TSA chapter met many families struggling with TS. She eventually quit teaching in order to devote more time to helping children with TS. Over the years, she observed hundreds of children in classroom settings, participated in IEP meetings in and around her hometown and shared her observations with teachers, parents and doctors.

I've known people who enjoyed selecting a word at random from a dictionary and reading about it just for fun, but here is a dictionary that anyone can read from cover to cover. That is, anyone interested in TS. Don't be misled by the name of the publisher. The book is primarily about Tourette Syndrome and "all the cousins" - OCD, ADHD, LD, etc.

I recommend this book as a purchase, not just a borrow.

reviewed by Ray Robertson

**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.*

Support Meeting Report

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

We continue to see good attendance at the monthly Parents Support meeting. Seeing new faces tells us the need is out there for support and the work of helping others who are trying to deal with Tourette syndrome is never finished. As always, our Kids Klub is a great way for kids to meet and talk with other kids with TS. Let us know how you and your children are dealing with the school year winding down. Are there issues that need to be addressed or resolutions to a problem that you believe might help somebody else going through some similar problem? Come and share your experience with us!

Our next 4 meetings are:

June 9/05
July 14/05 Annual Family Mini-Golf Night
August, 2005 – Summer Break
Sept. 8/05

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)

Your Membership

Is your membership up-to-date?

As a member of the TSFC you receive:

- the National newsletter 3 time a year,
- our London Chapter newsletter 4 times a year,
- a discount when you purchase TSFC materials,
- a special member rate for conference registrations,
- a vote on business issues at the Annual General Meeting. If you are not able to attend you can give your vote by proxy to another member,
- the warm feeling that you are helping other TS families.



CPRI Brake Shop: Putting The Brakes On Impulsivity

In any given situation (a person says hello to you, someone takes a step onto your sandcastle, or a girl kisses you), there are many different ways that a person can respond. What most people do is to make a decision of how to respond based on a lot of different information. What do they think of that person? How do they want that person to think of them? What did they do the last time? Did that response last time go over well?

It is a good thing that most people think things through like this: the first impulse most people have of how to respond in a situation is usually a pretty bad idea. **Imagine, then, if you couldn't hold in your initial idea or thought, because the brakes in charge of doing that were a bit 'leaky'.** Besides being constantly on the move or talking then, lots of times you'd be saying or doing the worst things you could possibly say or do in a situation, **EVEN THOUGH YOU KNEW BETTER!** How frustrating!

This is called Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type (ADHD-PHI). A good way of thinking about ADHD-PHI is summarized in the following quote by Dr. Russell Barkley: **"ADHD-PHI is a problem not of knowing what to do, but doing what you know"**. A computer might have some really great games on it, but if it doesn't have any RAM then you can't run any of them. In the same sort of way folks with ADHD-PHI may have remembered lots of good ideas about what to do, when to do it, and who to do it with but they can't pull that information up quick enough when it really counts. Before you know it, you have already 'gone with your gut' thanks to that leaky brake. Individuals with ADHD-PHI often have what I call an **"Oh Crap" face** – it's the expression they get when the correct solution (what they REALLY wanted to do) comes to them AFTER it is too late. The "Oh Crap" face proves that these individuals aren't being purposefully bad.

For example, a set of parents might say that their son seems incapable of not bothering his younger brother on a trip in their van. It may very well be that the elder brother intends, and wants, to follow this rule but nevertheless acts 'in the moment' as he is lacking the pause necessary to remind himself of the rule, the consequences, and even his own preferences in the matter.

Because of this, a number of skills that require a 'pause' be inserted between incoming information, and a reaction to it, are going to be lacking. These skills include **managing time, solving problems, talking to yourself inside your head, metacognition** (thinking about thinking), **applying something you learned in one situation to a new situation**, and being able **to hold it together** when something doesn't go the way you wanted it to. Recognizing these deficits is the first step in finding 'detours' around them, or accommodations for them, so that problems are minimized.

So let's give 'em a brake!



There are all sorts of **medications** that help to get this brake working better, and they are effective enough that you should talk to your physician about them. Some pills you take once a day (like **Concerta**), some you take more often (like **Ritalin**), and some you can break up and sprinkle on your morning cereal (like **Adderall**). Some work for just a little while in the day (like **Dexedrine**) and some continue working all day every day (like **Strattera**). People used to worry about these medications for a number of reasons:



For one, many thought these medications could lead to drug abuse in individuals with ADHD-PHI. Actually, it ends up that people with ADHD-PHI are **less likely to abuse substances if they take medication**.



There was also a concern that kids on these medications wouldn't grow as tall, or eat as much as kids who weren't on these medications. It is true that many of these medications make you less hungry when you are on them, but usually this means that you just eat MORE when the medication wears off. And while you may not grow tall as quickly as your friends, **by the time you are an adult you will have caught up in height**.



Finally, some people used to believe that these medications might give you tics (involuntary movements or sounds), or make any tics you have escalate. It ends up that this typically doesn't happen; in fact tics **LESSEN** in as many people as they **INCREASE** in. Plus, **even when the tics DO increase, often this increase is only for a little while**.



Medications insert that needed pause between event and response – they give you an inner workbench to sort things out on – but they can't fix all of the things that went wrong during the times your brake was leaky. Don't assume, then, that the medication will suddenly make up for years of missed learning and don't think that the medication "doesn't work" if this doesn't happen. Remember this about medications: **Pills Don't Teach Skills**. Once you have that brake, you still have to learn how to use it! Expect to be behind in certain skills, and to have to spend time getting caught up.



The techniques described below are far more successful when medications have already tightened up the leaky brake; this is one of those times when **medications and behavioural techniques work much better together**.



"Anticipate and Avoid" strategies are very helpful in avoiding the set-up that can occur when EVERYONE wants things to go a certain way, but because of leaky brakes the individual with ADHD-PHI is incapable of pulling it off without accommodations. To illustrate using the example above of the brothers in the van, perhaps the brothers can be separated preventatively at the onset of the trip, with one parent in back and one in front, rather than waiting for the inevitable failure and the frustration it breeds.



Implementing a system requiring the individual to count to a certain number between an event and his/her response to it may help increase insight into a reactive response style, allow other response options to occur to him/her, and train that needed but missing pause.



Continue to **establish structure** in the person's life. It may take a long time for it to become automatic, but it is still very helpful. It will help to make transitions easier as fewer shifts will be unexpected ones. It will also put fewer demands upon working memory (that "pause" we said wasn't working very well), as many aspects of the day will consolidate into habits and so you don't HAVE to remember them anymore – they are automatic. Finally, it is often in unscheduled times that these individuals find themselves in trouble, as it increases the chances that (s)he will respond impulsively to something or someone.



It may help retention of the structures/schedules to **make them visual** (e.g. a picture-board of his morning between when he wakes up and when he leaves for school). Aim to have rules, consequences and routines so predictable that the individual can finish your sentences for you. This will help him/her to feel more independent and in control as well.



Use **immediate, explicit 'token' rewards** for accomplishing tasks, that can be accumulated and 'cashed in' for extra privileges or snacks or other desired items (decided upon in partnership with the individual). This will help children with ADHD/PHI to "keep their eye on the prize" and increases their ability to comply with requests.



This need for visual structure and a reward system should be considered when choosing new teachers, and also when planning for times that are traditionally quite unstructured (such as recess, or time on the bus).



Without a brake to tell you to keep your thoughts to yourself until you have decided what to say out loud, EVERY thought these individuals have may be said out loud. In fact, they may get in a lot of trouble for talking ALL THE TIME. This is called "**pressured speech**", and it is what would happen to ANYONE who doesn't have a filter between their thoughts and their mouths! In a way it isn't fair – OTHER people get to keep certain things to themselves. That's why it is not only important, but also respectful of the person with ADHD-PHI, to learn to **distinguish what is intended to be "inner private talk" and what the individual actually means to share**. Things meant to be inner private talk should not be reacted to or judged. Maybe a notebook could be provided as a place for this talk or these images to be put.



Help to **train the individual to be more deliberative and less impulsive in his/her decision-making**. Proper decision-making involves brainstorming different solutions, walking through the potential advantages and disadvantages of each of those solutions, deciding which solution to go with, and then evaluating how successful that solution was. As individuals with ADHD-PHI will show difficulty in automatically doing this internally, model how this looks externally and explicitly. Role play identifying what the problem is, generating possible solutions, discussing and even writing down the predictable consequences of each solution, evaluating and ranking each solution, implementing the best solution, and taking note of the outcomes.



Help the person identify certain staff, family members, or friends to be "**impulsivity checkers**" – individuals whom (s)he can go to in order to help him/her with this process.



Language mediated strategies can sometimes help children concentrate and control their behaviour. For example, **when given instructions the individual should be asked to repeat them** in his/her own words to ensure that (s)he understands what is expected. This strategy can also be helpful as (s)he is doing work to help him/her focus in on the task.



Individuals with ADHD-PHI are, by definition, poor at time management; **the passage of time must be made more explicit and visual** for these individuals. Sources of stress might be: knowing when you will be done a certain task, or mistakenly feeling that one's entire week is filled with appointments with no time left for fun. By providing visual outlines to look at (e.g. a pen to scratch off each step as it is completed, or by showing the

individual what appointments (s)he has and when on a calendar), more security can be infused into the situation, keeping frustration levels lower and distractions to a minimum.

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Winning the Homework Battle

Susan is a Grade 4 student with TS and ADHD. She is an average student in most of her classes, but is struggling a bit with her math and with English, especially when she has to do creative writing. Her teacher assigns homework every night. Susan goes to a sitter after school and her parents pick her up in time for supper. After supper, Susan's parents take turns working with her for 1½ to 2 hours trying to get homework done. Susan spends most nights upset and crying. Both her parents are frustrated and don't understand why she can't just get the work done.

Unfortunately Susan's case is quite common among families who are dealing with Tourette Syndrome and its associated disorders. Homework is a battleground. In most cases, the battle is fought daily, and everyone seems to lose. The parents lose most of their evening to assisting, begging, cajoling, disciplining and so on in an effort to get the student to do the work. The student loses play time, time with their friends, and recreational activities. Worse still, many lose their self-esteem over the struggle.

Homework should not be causing this much of a problem. There are several steps you can take and strategies you can employ to make homework less of a struggle.

- **Understand what is going on with your child during the school day.** Most TS kids spend the day trying to cope with their tics, focus their attention on school work, and deal with other symptoms of their disorders. Sometimes by the time the school day is over, they may be so exhausted or over stimulated that they may not be able to manage homework.
- **Talk to your child's teacher.** Find out what the expectations are for homework. Communication is important. It is easy for parents to get so anxious about their child "keeping up" or "appearing normal" that they will spend several hours a night working with their child on homework. In Susan's case, her parents brought up the homework battle at a parent-teacher conference and the teacher was horrified that the homework was causing so much problem. She had no idea that this was nightly occurrence. She expected her students to spend about 20 minutes working each evening. Now, as long as Susan does her best to work for 20 minutes, that is all she is required to do. The teacher has modified some of her assignments and is making sure Susan gets extra help during school when she needs it.
- **Maintain a communication log.** Most schools provide an agenda to their students, and most teachers expect students to record their homework assignments. Check it daily to see what work your child needs to do.
- **Sometimes homework is impossible.** There will be times when your child's symptoms or problems with medication will result in homework being an impossibility. When this happens, let the teacher know in the communication log, by phone, or by e-mail. It is important to teach your child that he is still responsible for the work. He will need to finish the assignment once he is able to. This might be during the school day, as extra work the next night, or on the weekend.
- **Set a specific time for homework.** Some students find it beneficial to have a routine in the evening that includes a time for homework. Students with ADHD may have poor organizational skills and lack an awareness of time. Just getting started on homework is the biggest challenge. Having a set time for homework helps to

overcome this. It is important to work with your child to find the best time for homework. Though you may find it most convenient to have your child do their homework right after school, this might be a time when your child needs to wind down. Also consider setting an alarm that marks the start of homework time. This removes the burden of you having to watch the clock, and it helps your child develop some responsibility for starting their work.

- **Take a break!** If your child is getting frustrated with their homework, take a break and allow things to cool off. Maybe a bike ride around the block will work off some of the frustration and will allow her to tackle the work.
- **Stay calm.** If your child blows up, stay calm and lower your voice. If you respond loudly and emotionally, the situation will escalate. The more emotional your child becomes, the less homework will be done. If you can stay calm, it will help your child cool off.
- **Have a duplicate set of books at home.** The biggest challenge to completing homework might be forgetting the books at school. If this is a chronic problem ask the teacher if a second set of books is available to keep at home.
- **Arrange for a homework buddy, or a study group.** Study groups are effective when your child is in middle school or high school. Getting together with a few other students who are working in the same classes can be a big help. If your child does not have all the details of the assigned work, he can get it from one of the other students. Studying for tests in a group is usually done by reviewing the material verbally. This increases the retention of material. Instead of just reading and writing the work, he will be discussing the material out loud.
- **Ask for written assignments.** Ask the teacher to provide written assignments with the due dates specified. Many students with TS and TS+ find it difficult to copy assignments from the board and may neglect to include all the details, or the due dates.
- **Ask if the teacher is using an electronic blackboard or homework website.** Some teachers are making use of technology and are providing information on assignments, due dates, tests, etc. on a website or an electronic blackboard. Parents and students can access the site from their home computer.
- **Post a colour-coded calendar.** Keep a monthly calendar of assignments, quizzes and due dates. This is a great tool for middle-school and high school students who are learning to become responsible for their own success by managing their workload. Mark dates for projects and tests. Studying should start several days before a test and at least 2 weeks before a major exam. Count back on the calendar and mark the dates when studying should start.
- **You don't have homework.** It is your child's homework and not yours. The drive to help your child, especially if they are struggling, is strong. However, if your help crosses into you doing the homework or projects, you are hurting your child more than helping them. Your child will be better off in the long run if you bring the problems he is having with a set of problems to the teacher's attention. Use the communication log to flag a problem, and, if necessary, follow up with a call to the teacher.

Like it or not, homework will be a part of our children's lives from early grade school until they are young adults. The investment in time and effort to resolve the struggle over homework will be worth it. In addition to reducing a major stress on your child's life, you will also be reducing your own stress and making family life more enjoyable, while helping your child build important skills.



-- Cathy Wylie



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

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