TS and OT

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Are you tempted to skip quickly over this article because you are so tired of educational acronyms that only serve to confuse you more. Before you do, take a moment to answer these simple questions about your child with TS. If you answer yes to any of these questions, I strongly encourage you to read on because you are not alone and there may be some answers.

How many of you have a difficult time buying clothes for your child?

Are you forever cutting tags out of the back of shirts, are you in a constant search for socks without seams and pants with an elastic waist?

How many of you have a child who is bothered by bright lights, loud or particular noises, certain smells, the feel of some fabrics?

How many of you have a child with TS who has very poor handwriting, who continually copies things wrong from a textbook, the chalkboard?

How many of you have a child who goes quickly into "overload" and becomes very easily out of control?

These are all behaviors that we see very frequently with children with TS. They are not motor tics or vocal tics, they are not obsessions or compulsions, but they are certainly very common with children with TS.

We don't have all the answers with TS, but we do know that there are certain co-morbid conditions that are seen in very large numbers of children with this disorder. One of these conditions is something called Sensory Defensiveness. I will try to explain it in so that you as a parent can understand what your child is going through. We have 5 senses and any of these can be heightened with children with neurological disorders such as TS. If your auditory sense is affected, you will find it difficult to tolerate certain noises or in particular,

loud noises. The auditory system has a difficult time sifting out noises in the environment, so even the quietest of noises which an average person may not even hear, can be very disturbing to you. I once had a young boy with TS tell me that the electric clock on his classroom wall drives him crazy. Electric clocks make a humming sound that most of us don't even hear, but if you are aurally defensive, it could take over your world. It ruins your attention span and if it's a particularly loud noise, it may actually hurt your ears. I had a boy in my class a few years ago with TS and every time the school intercom came on, he would cover his ears. It was just too loud for him to tolerate. Another young boy could not tolerate the sound of his father chewing. He described it as being as offensive as nails scratching across a chalkboard. Dinner time became a time of constant battles and outbursts until the family finally agreed to have the father and the child take turns eating in the living room.

A very large number of these children suffer from tactile defensiveness. They cannot stand to be touched suddenly, They cannot wear certain fabrics, fabrics that are not soft and supple. They hate tags in clothes, anything with obvious seams, long sleeves, turtle neck sweaters and the list could go on and on. If children with this condition are forced to wear something that is tactually defensive to them, their behavior will most certainly be affected. A good comparison that will put you in the place of that child would be imagining the worst sunburn you've ever had and being made to wear a wool sweater. And then once wearing that wool sweater, you must walk through crowded hallways where you are constantly bumped into by other children, you must go to gym class and play basketball and all of the other activities that a child must do in the course of the school day. What kind of a mood would you be in at the end of that day?

Children who experience these types of sensory defensiveness often find it very difficult to maintain control in situations that are over stimulating to the senses; for example, crowded hallways, the cafeteria, the playground and the school bus. Imagine trying to navigate through a crowded middle school hallway during change of classes wearing a wool sweater over a bad sunburn and when every noise is at a volume louder than anyone could tolerate.

And what about this terrible handwriting? A very large number of children with TS also have a co-morbid non verbal learning disability in the area of fine motor and visual motor impairment. Translated this means that their hands cramp very easily when they write and that writing is very slow and laborious for them. It also means that after one or two sentences their handwriting deteriorates to the point of being illegible no matter how hard they try. They especially struggle with cursive writing. It also means that they have a very difficult time copying things accurately from a chalk board or textbook, they tend to reverse letters and they don't line math problems up correctly to name a few. Being unable to write is extremely interfering to classroom performance. Homework takes them twice as long, test are never finished on time, math problems are wrong because they were not lined up properly and the level of frustration grows and grows each time they must put a pencil or pen in their hand.

So, how does an OT fit into this picture? Some of you may even be wondering what is an

OT. **An OT is an Occupational Therapist** whose job it is to see that children with disabilities of any kind learn to function to their optimum potential. **I always strongly encourage any parent of a child with TS to request an evaluation by the school's occupational therapist including a sensory integration evaluation** to determine the extent to which this disability is impacting on their educational performance. OT's traditionally work with children with fine motor impairments to help them improve first and foremost their fine motor skills, but even more importantly to determine what adaptations need to be implemented in the classroom setting to assist the child with this problem. Below is a list of very useful accommodations that can be in the child's IEP or 504 Plan to address these issues:

The use of a word processor is a reasonable and necessary accommodation.

Occupational Therapy Intervention / Sensory Integration Evaluation.

Tests/reports given orally. Waive time limits on tests.

Shorten assignments.

Verify all homework assignments to make sure they were copied accurately.

Standardized tests answers written directly in the test booklet and transferred onto answer sheet by teacher or assistant

Provide graph paper to help line up math problems or allow child to turn paper sideways.

Do not penalize students for poor handwriting. Provide alternatives for doing tests, assignments, etc. (orally, taped).

Do not penalize for spelling errors. Encourage the use of spell check.

Provide class notes rather than having the student copy from the chalkboard or overhead.

Having said all of the above, I also must add a caveat to all of this good advice. It is not at all uncommon that school based OT evaluations miss the problem of fine motor difficulties with children with TS because they tend to give a very short writing sample. I recently worked with a young girl with very obvious (to me, at least) fine motor difficulties. When tested by the school OT, no disability was found. When I asked to see the writing sample that the OT had asked for during the evaluation, I was shocked to see that he child had only been asked to write his name and one other sentence. The sample demonstrated fairly good handwriting. Most kids with TS can write a few sentences with decent handwriting. However, this quickly falls apart as their hand begins to cramp and the handwriting deteriorates. I then had the

classroom teacher put together a portfolio of longer writing samples from the child in question which quickly demonstrated her inability to write neatly, stay on the line, space appropriately between words and keep even margins. Her math papers showed uneven addition and subtraction columns and therefore answers that were incorrect. You also need to know that school based OT's are not always trained to perform sensory integration testing.

When either of these situations occurs; 1) the school based OT evaluation does not find any fine motor difficulties and/or 2) the the school OT does not evaluate for sensory integration difficulties, you have the right as a parent to respectfully disagree with the OT evaluation and request that the school do outside OT testing at their expense. And even more importantly, if your child is exhibiting any of the signs of sensory defensiveness listed at the beginning of this article and if the school does not perform sensory integration evaluations, you have the right to request that it be performed by an outside OT at the district's expense.

Children with sensory modulation difficulties will often experience periods of over or under arousal. Behaviorally this manifests itself as poor coping mechanisms, withdrawal from activities, increased aggression toward others, increased frustration and/or anxiety when confronted with situations perceived as overwhelming or threatening. Children with these issues may also attempt to maintain control over their environment to a very extreme degree, becoming inflexible and stubborn. Their inappropriate behavior may be driven **not** by an emotional need, but rather a physical one.

The good news is that children with these difficulties usually respond well to occupational therapy. The therapy should focus on the underlying sensory processing and modulation problems.

To summarize, if this article seems to have been written about your child, you must immediately become best friends with the school Occupational Therapist. Seriously, follow the procedure outlined herein, have your child properly evaluated and you may soon see a very different child.

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