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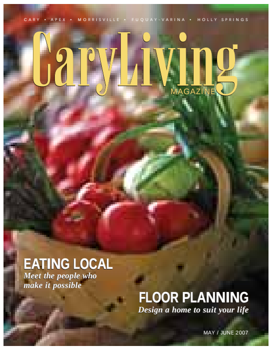

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"Stop it!"

UNDERSTANDING TOURETTE SYNDROME

By Julianne Winkler Smith

You're sitting in a restaurant, ready to enjoy a nice, quiet meal with a friend, when you hear loud noises coming from the next table. A family is seated there, and one of the kids seems to be making that bothersome, repetitive shriek-like noise. As you look over (with a bit of a glaring eye), you notice that the child not only continues to make this incessant sound, but his parents are doing nothing to quiet him. (Don't they know how annoying that is to the other diners?) You try to catch the mother's eye – certainly your best "aren't-you-going-to-do-anything-about-that" stare will get results.

But it doesn't. They completely ignore your efforts and your growing agitation. You anxiously look around for a server so you can request a new table … you just want that noise to STOP.

He's sitting with his family in a restaurant, ready to enjoy a nice meal. But, as always, the noise is there. That incessant, repetitive shriek-like noise. He notices a woman at the next table staring – well, glaring (just like most times when they go out to dinner). Thankfully, his parents and sister do nothing to quiet him. He catches his mom's eye and she lovingly gives him her best "it's-OK-honey" look. He tries to quiet himself – hoping just this once he'll get results.

But he doesn't. And the more he tries to stop it, the more frequent and loud it becomes. He's learned to live with the annoyance and frustration. But still … he just wants that noise to STOP.

This is Tourette Syndrome. It is estimated that over 200,000 people in the United States have this neurological disorder characterized by sudden involuntary motor and vocal tics. And the majority of those people whose lives are marked by constant grunting, twitching, squeaking, shrieking, and flailing are children.

You've probably heard of Tourette Syndrome (TS) before. Most likely, you've laughed at a comedian or a sitcom that used the disorder in relation to a cursing outburst – and maybe that's even how you define TS …"That cursing disease."

And because there is little media attention given to Tourette Syndrome other than this sensationalized aspect, the general public has a poor understanding of it. So first, it's important to note that there are a few things TS is not. It's not a disease and it isn't contagious. And yelling out profanities and racial slurs (called "coprolalia") is not definitive of the disorder – in fact, less than 15 percent of people with TS manifest these symptoms at all.

So what is TS? Typically, Tourette Syndrome begins showing itself at age six or seven, with the most common first-presenting tics being eye blinking and throat clearing. But due to the nature of these tics, children are frequently misdiagnosed as having other conditions, such as allergies and asthma, or visual problems. And because TS is rarely on the doctor's radar, often multiple medications are prescribed to treat these symptoms, leading to incredible frustration for everyone when the symptoms are not alleviated by this course of action.

So how is Tourette Syndrome diagnosed? Currently, there are no medical tests available to identify TS, but rather it's based solely on observation and a symptom history that has to fit into a specific neurological definition. Family history is vital too, as the condition is genetically inherited. (Although not specifically identified, the gene(s) for TS have been found to be dominant; however, in past generations it could have manifested as a milder tic disorder, as opposed to full-blown Tourette.)

Much liked Autism, Tourette Syndrome is what's known as a spectrum disorder – cases range from very mild to very severe, and the tics will wax and wane in type and severity over time. One day a child may be squeaking every three seconds, the next he might be grunting. Or a particular vocal or motor tic may last for years. Sometimes a person is completely unaware that he or she is ticcing, while other times there is a preceding urge, like with an itch or a sneeze. Sometimes it's possible for a child to temporarily suppress tics (for seconds or for hours), but the tics ultimately must be expressed and usually are in an explosive manner.

Although there is no "typical" case of TS, there is somewhat of a natural course: Onset around six or seven, the highest tic severity usually between eight and into the early teens, and a marked improvement in symptoms in late teens/early twenties. As many as one-third of TS patients experience remission of their tic symptoms in adulthood, with most living satisfying, successful lives.

As if it weren't enough, tics are not the only characteristic of Tourette Syndrome – and actually, they can be the least impairing symptom. About 50 percent of kids diagnosed with the disorder also have Attention Deficit/Hyperactivity Disorder (AD/HD). And although most kids with TS have obsessive thoughts and compulsive behaviors, about a quarter of them will have severe enough symptoms for a diagnosis of Obsessive-Compulsive Disorder (OCD). Moreover, whether it's due to the tics, OCD and/or the AD/HD (or a combination of these and several other associated conditions), kids with TS often experience significant learning disabilities. (Often these associated conditions are what ultimately lead to a diagnosis of TS, with the tics being an "oh-by-the-way" parental report to a health practitioner.)

But the child battling all these internal demons knows one thing to be true: They may be able to suffer in silence through their obsessive worries, frequent distractions or learning struggles, but their ticcing will rarely go unnoticed by others.

"The most challenging aspect of living with TS is probably the teasing and staring," says 13-year-old Jordan Williams of Raleigh. Jordan was diagnosed when he was 10, and has endured some pretty tough seasons with severe, debilitating tics. But through Jordan's journey with TS he's learned that his peers often just need to be informed. "Once other kids know about my TS, it doesn't bother them anymore – when someone who doesn't know makes fun of me, kids who do know about me are quick to stick up for me."

Campbell Johnson clearly recognizes the lack of awareness about his Tourette Syndrome. "People just don't understand it," says the Durham 12-year-old. "At the beginning of sixth grade, there was a boy who was so scared of me he would scream when I came around."

Campbell got his diagnosis when he was eight, so he's had four years to learn how to deal with the gawking and ridicule. And although he understands the importance of educating people about TS, he best deals with his symptoms through a shift in his own attitude. "I know I'll always have to explain my TS – I can't pretend I don't have it … but I guess I don't care what people think about me anymore."

For a child with Tourette Syndrome, it really takes a little of both – the willingness and patience to educate others, along with a strong sense of self-acceptance. Two tough items on a to-do list filled with things such as homework, sports, music, etc. You know, kid things.

“What I want people to know is that I am just a regular kid,” asserts Campbell. “I just make some noises.”

Jordan wholeheartedly agrees. “Don’t make fun of people with Tourette Syndrome. They go through so much, they probably don’t need to hear what you have to say.” His seriousness shifts to an encouraging tone when he adds, “Try to be friends with them … who knows, they may end up becoming your best friend!”

The Tourette Syndrome Association gives out a card to individuals with TS – it’s like a medical ID bracelet, of sorts. Just as the bracelet identifies a person to have a particular medical condition, so does the card serve those suffering from Tourette Syndrome. If someone is staring, gawking, or even has the audacity to make a “corrective” remark, the card comes in quite handy. It simply reads:

> “WHY DO I ACT THIS WAY?
> BECAUSE I CAN’T CONTROL IT.
> I have Tourette Syndrome – a medical condition. It causes me
> to make loud sounds, have twitches and say things I don’t mean.
> I can’t help it any more than you can stop a sneeze or cough.
> I’m sorry if it bothers you – it bothers me more.”

So next time you are in a situation where you are confronted with some odd behavior, someone who is perhaps annoying you by their words or actions, and you feel quick to judge or say something … stop and think for a moment.

Maybe the person can’t help they way they are behaving. And maybe, just maybe, their behavior bothers them a little more than it does you.

As with most things in life, awareness is the key to understanding. Understanding, the key to acceptance. Believe me, I know.

Before my son was diagnosed with Tourette Syndrome last year, each day was filled with, “Quit that!” and “Why do you keep doing that?” I was annoyed, frustrated, angry. I didn’t know why he couldn’t just STOP IT.

Neither did he.

But now we know. We’ve come to understand this disorder a little better, along with all its associated conditions. We still have a lot of learning to do, and we always seem to be dealing with some new aspect of TS and how it affects his life. But we’ve accepted Tourette Syndrome for what it is – and what it’s not.

My hope is that you do, too.

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If you’d like more information about Tourette Syndrome,
please visit the official Tourette Syndrome Association
website at **www.tsa-usa.org.**