

IF YOU ONLY KNEW THE MENTAL ENDURANCE OF YOUR CHILD

The mental endurance of a child living with Tourette Syndrome (TS) and its "tag-a-long" friends, Obsessive-Compulsive Disorder (OCD) and Attention Deficit Disorder (ADD), is amazing. Amazing in the amount of tenacity, energy, and focus required from the moment they wake until the moment they fall asleep – every day. The mental battles of ‘tug-of-war’ never cease. Some battles are easier than others, but it is a rare moment when something external is not igniting their tics and obsessions into constant motion. It is a daily struggle in which there are no rest breaks. The concept of never being able to turn something off is difficult to comprehend unless it is your daily way of life.

The battles I am referring to, which are unseen to you and everyone else, are the ones in which your child is constantly trying to control their tics and obsessions. The amount of energy and focus expelled to control these tics and obsessions is both enormous and exhaustive; leaving little energy to perform all the typical responsibilities required of a child – like paying attention in class, completing homework, completing chores, and being social. Many situations, such as when I sit in a conference or meeting, similar to your child sitting in a classroom, can seem like someone to my left is singing, someone to my right is banging erasers together, and someone behind me is pulling on my collar. How am I/your child supposed to have the energy to also focus on the speaker/teacher when we are constantly trying to block out these distractions/control the tics and obsessions?

If you are a parent of a child living with TS, and possibly OCD and/or ADD, you understand your child’s feelings and needs more than anyone. You observe their struggles in each facet of their life as well as the bothersome, sometimes intolerable side effects of neuroleptic medications. However, unless you yourself live with these disorders, you are unable to comprehend the level of mental endurance that resides within your child's brain.

The best way I can serve you, other than ensure our organization offers programs and services that assist in improving the quality of life for you and your family, is help you better understand the mental challenges your child endures on a daily basis. While your child may be able to express how they feel, maybe even in some detail, they may not be able to articulate the struggle TS and OCD truly creates. I will attempt to share my thoughts with you, when my tics and obsessions occur, in hopes of providing you with a better understanding of the mental strength required for a child to succeed, or just get through, each day. I say ‘attempt’ as I have not explained to anyone, in much detail, the endless ‘ticker-tape’ of tics and obsessions that flow through my mind.

It would be impossible to express, in the space of this article, every tic and obsession that occurs in just one day. Therefore, I have decided to use a recent event as my ‘stage’. I completed an ultra-distance triathlon (2.4-mile swim, 112-mile bike, 26.2-mile run) in Cozumel this past November. My goal is to simulate my experience at this event to what a typical school day is like for a child with TS (and related conditions). Try to imagine all the interaction in your child’s daily life while constantly, silently, having to fend off these ‘intruders’ in their mind.

A DIFFERENT KIND OF RACE REPORT

It is common for individuals to write a race report after they have finished a long endurance race such as this one. Simply access a specific race event page on Facebook to find a current read. Topics such as difficulty of the course, weather conditions, how the person felt throughout the race, and other highlights specific to that race are detailed. For most, finishing time determines the success of a race.

I usually let out a ‘hmmhh’ after reading most race reports and think... ‘If it was only that simple!’ Of course, I am not disrespecting anyone that, not only completes, but, participates in an event of this

distance. As you can imagine, the physical discomfort and pain that must be endured can be harsh. However, the physical pain pales in comparison to the challenges TS and OCD bring to my race day – mentally and physically.

My race report will mirror the unpredictability and occurrence (of tics and obsessions) you observe in the daily life of your child. That is, my report will be filled with random statements, incomplete sentences, and random outbursts. Again, I will attempt to describe a similar scenario, in your child's day, by inserting my comment in brackets. I will also insert random obsessive thoughts or actions by simply inserting 'OBS' at the start of the sentence.

AN IRONMAN TRIATHLON ON TS & OCD

My race begins a couple of days before the canon, signifying the race, is even fired on race morning [anxiety begins to build in your child before even stepping on the bus or arriving at school] - from the never-ending stimulus at the airport, being confined on the plane, to the race expo – constantly having to develop strategies which will cause the least anxiety and avoid the most attention [your child is, essentially, developing a battle plan to maneuver through their day with the path of least resistance – avoiding what I call 'tic zones'].

The heightened level of anxiety upon entering the race expo [classroom or lunchroom] is similar to the feeling you might experience after you've had a near-miss car accident – rapid breathing, a rapid heart rate. These intense anxiety filled situations do not occur often, but the 'electricity' flowing through me is high once I realize I am about to enter one. I usually purchase a hat and a shirt at each race expo and then peruse the vendors. To simply buy a hat, or anything else, I, for what seems like minutes on end, search every item on the rack, in microscopic fashion, looking for the tiniest of anomalies in stitching, discoloration, and any other imperfections (imperfections that most would need a microscope to see!). The feeling everyone is watching and wondering what I am doing (dissecting every item on the rack) brings out my tics in full force.

To ensure this article is not mistaken for a novel, I will get to the actual event...but, I hope you get my point of the endless distractions which create havoc throughout your child's day.

The first place you arrive on race morning is a transition area where your bike is racked (from the day before). At this race, you had the option to rack (hang) your bike with the front tire facing in or out (usually the bikes are required to be racked, facing the same direction). OBS: I have to go around and ensure all 2,500 bikes are facing the same way.

Bike techs are available onsite to inflate your tires. These techs are quite knowledgeable, so when you inquire more than once if both tires are inflated to 110psi (I mean right on the 110 hash mark of the bike pump) you receive a raised eyebrow [the look you see others frequently give your child]. Of course, as I roll my bike away, I am still wondering if the tires were actually inflated to 110 [your child may know they answered a question correctly, but erased it numerous times because it just didn't look right]. Many with OCD constantly redo something repeatedly even when they know/see the desired result (i.e., door is locked, light switch is turned off). Next stop: Drop off bike and run special needs bags, which contain items you may access at a certain location in the race (the items are too bulky to take with you on the bike or run). There were four or five school buses with young kids hanging out of the windows, none who spoke English, who you would hand your bag to (special needs bags are identified by a sticker with your race number and sorted when you reach them on the course).

OBS: With 2,500 bags, for both bike and run, there is no way they will properly sort these bags, much less, find mine when I get to the designated location. Everyone probably has these same thoughts, but I'm sure they pass quickly. However, OCD doesn't allow a thought to leave the 'vault' in your brain until another obsession has come along to replace it [while a child may appear to be listening to their teacher, a majority of their energy may be focused on an obsession they are unable to remove from their mind]. Each athlete is provided with a timing chip, which can be attached around the ankle with an ankle strap.

OBS: I lean down, repeatedly, before the race to unstrap/strap the Velcro to ensure the chip will not come loose during the race – which then causes obsessing about the stitching tearing due to the repeated strapping/unstrapping.

Swim start: There is a lot to obsess and tic about [standing in a long cafeteria line] with 2,500 anxious, excited, nervous people standing around – the air is consumed with all this energy. Everyone is required to wear a swim cap, during the swim, which has a different logo on each side.

OBS: Some are wearing the cap with the race event logo on their right side - some on their left. This is out of sync and we can't move forward - they should have told everyone the event logo has to be showing on the right side of your head (keep in mind, there are much more important things to be focusing on at this moment).

New situations or experiences easily serve as a catapult for tics and obsessions for your child. While I knew this swim would be different than a swim in beautiful Galveston Bay, I failed to realize the obsession I was about to encounter. Wow, water so clear I can see the bottom 40-50' below!

OBS: Uh-oh, wait a minute, the coral on the ocean floor is dark and the sand is light. I can't swim over the coral so I guess I'll have to maneuver around so I only swim over the sand.

There are times when your child is able to overcome an obsession, although with great difficulty, when they are aware of a very negative outcome. While I did 'zig-zag' through portions of the swim course, I knew I could not completely fulfill this obsession as I would miss the swim cutoff time. Keep in mind, others are swimming around you. You will constantly swim into slower swimmers with faster swimmers swimming up on you.

OBS: Okay, someone just touched my foot with their hand – they better touch my foot with their other hand! Whoops, I touched someone's foot – I have to touch their foot with my other hand!

My favorite part about the swim: No tics.

Transition 1: Once exiting the water you are directed to where the bike gear bags are located (holding your helmet, bike shoes, sunglasses, etc.). The first thing I notice about the remaining gear bags, which are hanging in three rows, one on top of the other, is some of the bags have the race number sticker facing where I can see them; the other half are turned the other way.

OBS: No time to go through these bags to turn them so all the race numbers face forward. My first major obstacle in the race lies ahead. Once you have collected your gear bag, you are directed into a changing tent (yes, male or female). Complete chaos resides inside this tent – think back to when you (boys, not girls) purposefully stepped on an ant bed to watch the hundreds of ants scurry around crazily. While every athlete in the tent is rushing, as if it is on fire, I casually walk to an empty corner at the far end of the tent. Here, I can slowly and methodically change and ensure every strap, zipper, and sock is on straight and lines up evenly with the other. I actually feel comfortable allowing my tics to exhibit themselves here because I know no one will take the time to research the noises coming from the other end of the tent [there are places and times when your child feels 'safe' in letting their tics take over – and you will probably find them there repeatedly once they have discovered a place where they feel safe].

Bike: You retrieve your bike once you exit the changing tent. After giving too much attention (again) to the remaining bikes facing different directions, I locate my bike.

OBS: Are my tires, which were inflated less than a couple of hours ago, still inflated exactly where I want them?

As an adult, my tics have been consistent in how they are exhibited. They haven't changed in years. As you may witness, your child's tics can come and go with new ones presenting themselves out of nowhere. Surprise (to me)! I developed a new tic soon after getting on the bike – the need to lift my front tire off the pavement. Not like a 'pop-a-wheelie' a kid would do, but the need to get just a half inch clearance off the road. With much frustration, I had to accept this new tic and prepare for it to occur over the next 100+ miles. After almost eight hours of having to satisfy this tic, my arms, shoulders, and back were all but useless [a child experiences this exhaustion from repeating the same tic all day].

Being a slower cyclist, I (properly) attempt to ride to the far right side of the lane. As on right lanes of most roads, there was a solid yellow stripe on this course indicating, obviously, hazards to the right. In addition to the constant pulling up on the handlebars to get the front tire off the road, I now had to focus on riding an exact distance to the left of this yellow line. Mentally, this yellow line represents my protection from riding off into the abyss (i.e., sand, ditch, bushes), which usually results in a crash...or a recovery with a fear that I just dodged a bullet.

‘HEY!’...is my most common verbal tic. Not the best vocalization if you are already trying to avoid attention. Many people with TS will admit the more stimulus in their surroundings – the more frequent and severity of their tics. I assume, when riding, it is the stimulus created by passing cyclists which fuels my urge to say ‘HEY!’ This occurs in every race and, not surprisingly, I often get a glance back from passing cyclists with just a glance or a return “Hey”. I laughed to myself after this race, as I do most races, thinking of other athletes talking with their friends and asking “Did you see that guy on the bike, popping a wheelie and saying “Hey!”

Transition 2: It was somewhat of a relief entering the change tent for the second transition (from bike to run) as it is not near as crowded as the first – due to my slow bike time. However, it is time for another set of rituals with socks, shoes, and anything else.

Run: I imagine your child’s tics worsen toward the end of the day. A day filled with tics and obsessions, as well as all the activities at home and school, leaves very little energy (to combat the tics and obsessions). My energy is low, after nine or ten hours, and I am now left with a low level of defense to fend off the endless barrage of tics and obsessions. The variety of looks from others does not bother me too much – I would probably look too if I heard someone saying “Hey!” – seems like a logical response. No one wants un-desired attention (especially kids), which is why there is this constant need to control our tics. The increased frequency of my tics brings additional challenges on the run ‘leg’ of a race. When I tic, my face goes into somewhat of a frozen grimace, or rigor mortis state, in which I am not breathing (also because I am making a noise). I have no way to determine an exact percentage, but I estimate I breathe between 75-85% of the time on the run – a significant time to not to breathe over a five hour period.

OBS: Her race bib is pinned crooked on her shirt (as are most race bibs on runners coming towards me from the opposite direction); those cups of Gatorade are all filled at different levels – which one do I grab? (at each aid station along the run course); his hat is crooked on his head; my shoe lace is not even with the other; a portion of the road ahead has a pattern/design in it - I need to step on/avoid certain segments or bricks and be sure to start this ‘maze’ with my right foot. Nothing like throwing in multiple games of hopscotch during a marathon! Of course, the ‘HEY’ is coming out similar to the pace of an auctioneer [the same meaningless thoughts that exist your child’s mind].

If I didn’t get your attention on the bike, I definitely did on the run! Due to the large number of athletes on the run course, I frequently find myself at a similar pace with someone five to ten yards ahead of me. While I don’t mind explaining to other runners next to me that I have TS, I don’t feel the need to yell it out to someone ten yards ahead. However, I’m always wondering what a runner directly ahead of me is thinking; hearing someone behind them constantly saying ‘HEY!’!

I do feel friendly on the run course as I’m sure a few hundred people say “Hey” or “Hi” back.

Finish: The awesome ‘high’ feeling experienced in the last few minutes far outweigh the months of training and challenges presented throughout my race. For a brief moment, unselfishly, I relish in my personal accomplishment of triumphing over a ‘foe’ that will most likely never go away. I triumphed because I fought through all my tics and obsessions, not allowing them to keep me from finishing what I started.

Once I return to earth, my objective is always clear - To hopefully serve as an example to your child, or anyone else living with TS and OCD, that they too have the ability to conquer their disorder(s) and accomplish their desires.

Of course, the tics and obsessions continue as soon as I cross the finish line.

OBS: Does the medal they are about to place around my neck in perfect condition? Does it have any scratches, discoloration, or imperfections?

Confidence, resilience, patience, and understanding are key attributes needed in overcoming TS and its 'sidekicks'. The confidence and resilience to know you will succeed (even after many failures) and the patience and understanding of one's challenges and limitations and how one will overcome them.

Numerous other tics and obsessions occurred during this race [just like there are tics and obsessions your child may have not shared with you – not necessarily for negative reasons], not documented here, but I hope what I did share provided you with a little more insight and understanding of the challenges a child with these disorders experiences daily. It is understandable how they may have difficulties in school, completing chores, and making friends.

TS and OCD cannot prevent your child from having a quality life. Over time, they will develop strategies to minimize the impact their disorder has on their life. If the disorder does not disappear entirely, with age, they still have the possibility of enjoying life as much as someone living without these disorders.

One advantage they will have: their mental endurance will far outreach most of their peers!

The most important suggestion I can offer to you is support your child when they do discover something which brings them hope and peace.

If your child has a desire to participate in a local event, such as a 5K run, please let me know. Schedule permitting, I would enjoy coming out and running alongside them and share their accomplishment with them!

Merry Christmas, Happy Hanukah, Happy Holidays!

Michael