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CHILD & PARENT
RESOURCE INSTITUTE



The Brake Shop Clinic Putting the Brakes On Tics



There are many things said about Tourette Syndrome that just aren't true – I think I should mention some of these things in case you've heard them and believed them:

- Tics **AREN'T** caused by a lack of discipline, and punishment for tics will **NOT** eliminate the symptoms (in fact, punishment may make them worse)! Rather, recent studies indicate that TS likely comes from genes inherited from both fathers and mothers.
- Tics are **NOT** done on purpose, although some tics can look purposeful if you do not understand conditions like Tourette Syndrome.
- **Very FEW** people (less than a third) with Tourette Syndrome swear – especially children and those with mild cases. When they do, it is in a special way that doctors who work with Tourette Syndrome can recognize as a tic.
- In fact, **MOST** people with Tourette Syndrome have **VERY MILD** symptoms that aren't very noticeable at all!
- Finally, it **ISN'T JUST KIDS** who have Tourette Syndrome – most people have it their entire lives, and it doesn't stop them from doing what they want at all! Like me – I'm a doctor who helps people with problems they are having (called a Psychologist) and I have Tourette Syndrome too!

Whenever people do different movements together, or make different sounds together, it is up to their brains to learn those patterns of movements and sounds and store them away for later so we don't have to learn them all over again the next time. In a way, **the brains of people with Tourette Syndrome work TOO well** – they learn and connect **TOO MANY** movements and sounds; not everything needs to be remembered for later, but those eager Tourette Syndrome brains don't seem to realize that! Eventually those brains have stored up **SO MANY** movement and sound patterns in **SO MANY** places they seem to **ALWAYS** be telling us to move and make noises! When that happens, we say that a person 'tics' or 'twitches' and has Tourette Syndrome.

So let's,



It will be important for all members of the family to work towards acceptance of the diagnosis. The more you accept the diagnosis, the less of a problem tics can be! This is for a few reasons. The less 'worked up' family members become over symptoms, the less they will occur. Also, the more family members are able to identify symptoms as certain skill deficits rather than purposeful behaviour, the less apt they are to get into a power struggle and the more everyone will be able to work together to problem-solve issues without being drained by undue emotion. Finally, acceptance of the diagnoses made (and recognition that many of these behaviours are borne of these diagnoses rather than from wilfulness) will present many new opportunities for coping success. An example of this is finding ways to allow a disruptive tic to come out in a modified, acceptable way rather than simply punishing the child for "not stopping".

You might be wondering – can anything be a tic? Almost! Tics follow 2 major rules:

1. Tics are made from things we do or noises we make **A LOT** – they are **frequent** movements and sounds
2. Tics are made from things we do or noises we make **THE SAME WAY EVERY TIME** – they are **stereotypical** movements and sounds.

Be careful then! Sometimes we might be doing or saying something over and over again, just joking around. If we aren't careful though, what we are doing or saying could become a tic!

Sometimes it seems like there is a devil in your head reading your thoughts and making the tics you hate the most the worst ones of all, and at the worst times! Don't worry though – that's not what is happening at all! It is **STRESS** that makes tics worse:

- Things like being tired or hungry or hot are stressful.....and will make your tics worse.
- Being in a room with a LOT of people or a LOT of stuff going on is stressful.....and will make your tics worse.
- If you or other people pay a lot of attention to your tic or point it out all the time.....that is stressful and will make your tics worse.
- If you really hate a tic, or are embarrassed by it, that is stressful too.....and will make your tics worse.

A strategy to try, then, is to pretend your tics are a pesky little brother or sister. Just as this little brother or sister will only bug you more if (s)he knows (s)he's getting under your skin, so will the tics. The best way to "get the tics back", or to "play a joke on those pesky

tics” is to pretend that they don’t bother you at all – laugh about them with others, or roll your eyes at that silly Tourettes.

One time we ALL get stressed is during tests – this can be made even worse for a person with tics because you are not only stressed out about the test, but you might also be worried about your tics coming out even more than usual and embarrassing you! Plus it might be frustrating for the other kids around you trying to write their OWN tests – they may not be able to concentrate because of your tics. A good strategy for the teachers to use, then, is to **have a separate room for you to write your tests in** so that you don’t have to worry about distracting others or being distracted yourself!

Sometimes tics can make our bodies sore...and **the more we are thinking about how sore our bodies are because of our tic, the more we end up doing that tic!** Ways to help us not think so much about our bodies, then, is to take a hot bath or shower, to get a massage, to wear a hot towel, or to go to a chiropractor or acupuncturist. All of these things will help to get rid of any pain our tic caused us or help us to relax, so we aren’t always concentrating on that tic.

Singing while listening to music, playing an instrument, or playing a hard video game keep you so busy your brain doesn’t have a chance to tell you to do your tics!

Going for a long run, swimming, or riding a bike can **‘use up’ all that energy that normally goes into the tics** – this means that you tic less! When you first start, the tics might still be there but eventually they run out of fuel and go away until after you are done exercising. These exercises can also help train you to be more aware of your body and to control it.

Having someone, alone or in partnership with you, **talk to your classmates about what tics are** (called a ‘Peer In-service’) can help a lot! Many times the problems that the tics cause have more to do with people’s reactions to the tics than the tics themselves; people with tics are often surprised at how having tics just isn’t “a big deal” to others once they understand what is happening. Creating an environment where you no longer have to feel embarrassed about ticcing, or feel the need to hold in your tics, can further decrease your stress and anxiety, helping you to concentrate more on school and tic even less!

If you are not quite ready yet to let the other kids know about your tics and are still working hard to try and hide them, you might want to **work out a kind of code-system with your teachers**. Whenever you feel you can’t hold your tics in any longer and you need a “tic break”, you use the code (for example, maybe you put a certain colour of post-it note on the corner of your desk). This tells the teacher that (s)he needs to ask you to do something for her outside of the classroom (for example, give you some papers to take to the office <wink, wink>). When you leave the classroom you can then go to the washroom or wherever you and your teacher agree beforehand that you’ll go so that you can let some of your tics out and feel less distracted!

Teachers: for this strategy to work well, be sure to pre-plan and organize it with the child. Establish a place for the student to go that is out of view of others (i.e. private) and is not in the office as this can send many unintended and false messages to the child and observing peers. Finally, remember that the point of this strategy is to REDUCE embarrassment – so don’t do anything that would work against this goal!

On our website (www.leakybrakes.ca) and taught in our clinic is a technique called the “Comprehensive Behavioural Intervention for Tics” or **CBIT** for short (we also just call it, “Tic Management” in the Brake Shop). It works very well for helping our brains to

'unlearn' some of these extra patterns it should have forgotten a long time ago, and doctor guidelines now strongly recommend that CBIT is one of the first treatments you should try!

Comprehensive Behavioural Intervention of Tics (CBIT) allows you to **target specific tics** you most want to get rid of, and for some people it can work even better than medications! It is much harder work than medications, though, and takes a little while before it works really well. **You need to be patient and not give up if you are going to try CBIT**, and you will want to use it first on those really pesky tics that hurt you, or make it hard for you to do schoolwork or the things you enjoy.

It is not unusual for individuals with TS to be able to **suppress** ('hold in') their symptoms. Just as a person can (with limited success) fight off an ever-mounting urge to scratch an itch, people who feel a rising need to tic (called a "**Premonitory Urge**") can have a small amount of power over when and how they tic. Hence, it is neither surprising nor strange for teachers or friends to see a very different 'you' than your parents do. It is also not unusual for a recess or lunch monitor to see a different number of symptoms than the classroom teacher. **Tics have got to come out somewhere**, so often the LESS tics one person sees, the MORE tics the next person will probably see!

Parents and teachers should know, though, that suppression is only a temporary solution; everyone eventually has to scratch their itch. **Holding in tics can increase symptoms of irritability, defiance, obsessiveness, and explosiveness while decreasing the ability to concentrate**, meaning that suppression can cause more problems at school and with friends than the tics themselves would have! People with Tourette Syndrome sense that they must release these symptoms somewhere and somehow, and will do so where they feel most safe, secure, and cared for. Hence, rather than feeling like a "bad" parent or teacher if someone is ticcing in your presence, you can take pride in that fact. Because **revealing tics is a measure of comfort with the situation and people around them**, this is in many ways a compliment to you!

Finally, parents, be sure you request that any relevant accommodations found on this hand-out are added to a formalized **Individualized Education Plan (IEP)**. An informal IEP need not be implemented or transitioned, whereas a formal IEP is a legislated process that also includes the **Identification Placement and Review Committee (I.P.R.C.)** that **must** be adhered to, under the Education Act, (Education Act, Regulation 181/98). Any child with identified special needs has access to this process.



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www.leakybrakes.ca

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