

Neuropsychiatry Clinic

Guide to Tics and Tourette Syndrome

This is information on assessment and management strategies for Tourette syndrome and tic disorders in the Neuropsychiatry Clinic. This is *only* a guide; each case needs individual care, which may require adaptations of what is presented here.

What is a Tic?

A tic is a repetitive movement, production of a sound, or even a complex behavior. It is not a habit. Examples of common vocal or phonic tics include grunting, throat clearing, and sniffing. Examples of common motor tics include eye blinking, facial twitching, and head-shaking. At one time or another most people have, an almost invisible twitching in a small bundle of muscle fibers around their eyes. This is not a tic. Tourette syndrome is a neurobiological disorder with strong genetic components. (Single tics are very common in children, and do not typically require treatment.) For the diagnosis of Tourette syndrome a person needs the presence of two or more motor tics and one or more phonic or vocal tics, which have been present more or less continuously for at least a year. Tics tend to change in severity and type, new tics appearing and old tics disappearing, especially in children. Tics often get worse when the person is under stress or excited, and diminish or disappear if concentrating on something or sleeping. These changes are temporary. The tics themselves are involuntary, however they can sometimes be controlled voluntarily for brief periods of time, but are ultimately irresistible. Tics may also increase when the person is relaxed and in a safe environment, and so the tics are often increased when the person comes home from work or school.

How is Tourette Syndrome Diagnosed?

An assessment for Tourette syndrome or tics is based on a clinical interview. This interview involves getting to know the family, and the history of the symptoms. The life history and background of family members is required in order to learn about the particular family's coping style and current stresses, if any. Information about the psychiatric history of family members assists with learning more about possible genetic vulnerabilities. A developmental history of the child, including his or her birth history, developmental milestones, school history and medical history allows the clinician to learn about the child's strengths and difficulties. The clinician will also check for a wide range of other symptoms. This is not meant to imply that a particular child is thought to have difficulty with all of these areas.

Some parts of the assessment are specific to tics and Tourette syndrome. The clinician will obtain a detailed history of the child's motor and vocal tics. It is important to determine the nature of the tics, their severity, the timing of the tics, and what factors make the tics better or worse. It is not the presence or absence of the tics themselves which determines the need for medication, but rather the

extent of actual impairment. Therefore a major focus of the assessment is obtaining a careful evaluation of how the tics are affecting the child's physical, psychological, social, and academic well-being.

Children with Tourette syndrome or multiple tics may sometimes have other types of co-occurring problems such as difficulties with attention, getting along with other children, poor self esteem, trouble sleeping, severe tantrums, or sensitivity to touch or sound. The assessment will therefore inquire about many other sorts of behavioral difficulties apart from tics to determine whether or not there are problems in any of these other areas.

At present there are no scans, biological or chemical tests which can confirm or rule out a diagnosis of Tourette syndrome. EEG's and CT or MRI scans are not generally helpful unless other problems (such as seizures) are suspected. The clinician who does the initial assessment determines the need for further referral to other professionals, such as psychologists.

What Happens to Most People With Tics?

Some families and children feel relieved when they learn more about tics and tic disorders. Other families are upset that their child has a disorder or "syndrome". Children may be puzzled and frightened by their tics, and then relieved to learn that tics are not uncommon and not their fault. Parents may have misunderstood tics as willful, and may feel guilty when they have better understanding.

Tics are common in school age children. Most children experience some reduction of tics during adolescence. This reduction can continue through their adult life

Tolerance of tics can be different: some children are really bothered by their tics, others are not. Some children are more concerned about other people's reactions to their tics. Children may try to suppress the tics temporarily in public, only to have to let them out at other times. Suppression takes a lot of mental effort and, therefore can interfere with concentration.

Tics can be affected by one or more of the following: excitement, tiredness, stress, illness. These factors do not cause the tics. Children usually let their tics out at the end of day, when they get home from school and when they play nintendo/computer games or watch television. This increase in tic-severity is unlikely to stay at that level or worsen.

Most children's future is more likely to be affected by associated conditions, if present than by the tics. Increasing the tolerance for tics and a sense of humour can have a positive effect on all concerned and can reduce the need for treatment.

What Treatments Are There?

1. EDUCATION:

There is a great deal of confusing, inaccurate, and outdated information about Tourette syndrome and its treatment. Understanding Tourette syndrome helps families to gain a perspective on tics, and to know how to explain them to others. Knowledge is the single best way to relieve the anxiety around "new or worsening" symptoms. Education about the nature of the disorder also plays an important role in preventing unnecessary treatment. Treatment always has to be customized and will depend on the child, family, and school's tolerance of the tics.

Tourette syndrome varies in its severity from mild and hardly noticeable (the most common situation) to very severe (often displayed by the media and on the internet). Information provided to parents must help them to know that tics are very individual and unlike in other medical conditions, there is not a predictable course that all tics take. This is the challenging part of tics. It is important that parents understand that some of the research which has been derived from more severe or complicated cases of Tourette syndrome may not be relevant to more mild cases. Understandably, parents of children with mild tics may be upset when they receive a neurological diagnosis. Education will help determine when medication needs to be considered as an option for treatment.

2. MEDICATION:

When the disorder is causing significant impairment the clinician, family and child may decide that medication is necessary. Information will be provided on what medication options exist to treat Tourette syndrome. (Only about 25% of the patients in the Neuropsychiatry Clinic have been, or are, on medication for tics.) Medication helps to dampen the severity of the tics in about 70-80% of children and adults, but there is presently no cure by medication or other treatment. The intent of medication is to reduce, not totally eliminate the tics. Because tics come and go and change anyway, the need for continuing treatment needs to be evaluated on an ongoing basis to prevent the child from being on medication unnecessarily.

If medication is prescribed for a child, it is important to have a baseline evaluation of symptoms, and to monitor outcome carefully. It is also very important to start with a low dose and increase the dose slowly. Parents should not alter the dosage without consultation with a physician. Finally, it is important that the child, family and other caretakers are involved in the process of education around medication and medication evaluation.

What to do About Other Questions and Concerns?

Please call Sharie Scheske, nurse clinician (875-2891).

Further information about Tourette syndrome may be obtained from the Tourette Syndrome Foundation of Canada (800-361-3120) or from the Tourette Syndrome Association in the United States (718-224-2999). Information can also be obtained from the Vancouver chapter of the Tourette Syndrome Foundation of Canada (604-732-3594) or a website that Dr. Roger Freeman has developed; www.tourette-confusion.blogspot.com

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