



## Preparing for Your Child's First Tourette Syndrome Doctor Visit

Tourette Syndrome (TS) is an often misunderstood, misdiagnosed and confusing disorder. Learning that your child may have TS can be emotional and distressing for parents, yet being given a formal diagnosis often provides relief. A diagnosis provides a context for better understanding the movements and vocalizations that your child has been experiencing and can help you to access support networks.

For a diagnosis of TS to be made an individual must exhibit multiple motor and at least one vocal tic (although not necessarily at the same time) most days for a period of at least one year. There are also other tic diagnoses that do not meet the full criteria for TS. A diagnosis of one or more co-occurring disorders (i.e. ADHD, OCD, anxiety) often comes along with a diagnosis of TS.



### What type of doctor should I see to get a diagnosis of TS?

A diagnosis is typically made by a neurologist, however a developmental pediatrician, a psychologist, or a psychiatrist may also be able to make the diagnosis. If you don't know who to see you can start with your pediatrician who may be able to refer you to a specialist. Whoever you see should have a good understanding of tics and TS.

### What should I bring to the doctor's visit?

You can begin preparing for your first doctor visit by writing down questions you would like to ask the doctor. Included among the questions should be a plan for the next steps and follow up. It can be helpful to keep a tic journal for a period of time, noting the types of tics, frequency, intensity and the date they began. This can be useful information to share with the doctor. Also be prepared to share your family medical history and the medical history of your child. Remember that you are the expert on

your child. It is important to share all relevant information with the doctor even if you think something is embarrassing or unimportant so he/she can gain a complete picture of your child's symptoms.

### Is there a test to determine if my child has TS?

There is no test to determine the presence of TS. The visit may include a neurological exam and the doctor will ask questions to get a full understanding of the range of symptoms – neurological, developmental, emotional and behavioral. As there can be other reasons for tics, it is possible that the doctor may do some tests to rule out the presence of other causes. Once a diagnosis is made, they will provide some education on the disorder, a treatment plan, discuss how to be proactive with others (i.e. family members, peers, school) and can connect you to support resources. Before leaving the visit make sure that you are clear on the next steps, which may or may not include follow up visits with the diagnosing physician.

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### What treatments should I ask the doctor about?

There are no cures for TS but there are behavioral and pharmacological treatments to aid in the management of tics. Comprehensive Behavioral Intervention for Tics (CBIT) is a behavior therapy provided by trained practitioners, that was designed to help people manage their tics. For more severe tics, medication may be an option. Recent guidelines from the American Academy of Neurology (AAN) recommend a “watchful waiting” to see how severe or disruptive the symptoms are before beginning treatment. The guidelines also recommend CBIT as the first line treatment.

If your child is diagnosed with a co-occurring disorder sometimes these disorders may present more challenges for your child than the TS. Doctors such as psychologists and psychiatrists may be able to help with the management of these disorders as well as the TS.

### Will my child need assistance in school? Will my child be able to participate in regular activities like other children?

Receiving a diagnosis of TS can be scary at first, however, it is important to remain calm. While they are faced with some additional challenges, children with TS (and the co-occurring disorders) lead normal lives just like other children. Acceptance of the diagnosis will lead to better outcomes. If you believe your child may need accommodations at school speak with their teacher, guidance counselor or child study team to discuss this. Your doctor may be able to provide suggestions for accommodations.

Your child may also have questions about their diagnosis. Reassure them that they will be able to manage their TS and engage in the same activities as their peers. Help them to learn to be self-advocates and build resilience. Let them know there are other children with similar challenges. You can remind them that there are very accomplished and successful people that have TS such as lawyers, doctors, carpenters, athletes and entertainers.