Tourette’s syndrome (TS), or Tourette’s disorder as it is frequently called, is a neurologic illness that begins in childhood or adolescence. The essential feature of TS is tics—multiple movements or vocalizations that are sudden, rapid and purposeless. Tourette’s syndrome is often treated by both psychiatrists and neurologists as many people with TS have other illnesses including obsessive-compulsive disorder (OCD), insomnia and attention deficit/hyperactivity disorder (ADHD).

What is characteristic of Tourette’s syndrome?

- Both multiple motor and one or more vocal (phonic) tics are present at some time during the illness, although not necessarily simultaneously.
- Tics are recurrent, non-rhythmic, stereotyped (the same each time) actions or vocalizations that can usually be suppressed for a period when a person focuses on stopping them.
- Less than 40 percent of people with TS have coprolalia (swearing or yelling out foul language).
- Most people experience a discomforting sensation prior to their tics that disappears after they carry out the tic.
- Tics occur many times a day, nearly every day or intermittently throughout a span of more than one year.
- Significant impairment or marked distress in social (at home or with friends), occupational (work or school), or other important areas of functioning.
- Onset occurs before the age of 21.
- Symptoms can disappear for weeks or months at a time and severity waxes and wanes.
- Most people experience less tics as they get older; nearly 50 percent of people have significantly less tics as they reach adulthood.

What are the first tics that may be characteristic of Tourette’s syndrome?

Usually, a facial tic, such as rapid blinking of the eyes or twitches of the mouth, may be the first indication a parent has that their child may have Tourette’s syndrome. Involuntary sounds, such as throat clearing and sniffing, or tics of the arms and legs may be the first sign in other children.

What other symptoms are associated with Tourette’s syndrome besides tics?

Approximately 50 percent of people with TS experience inattention, hyperactivity, and other distressing symptoms that are characteristic of ADHD. In some people, these may actually be the most frustrating and worrisome symptoms of their illness. People with TS are at increased risk for developing anxiety disorders.

Approximately one-third of people with TS experience severe and impairing obsessional thoughts and compulsive behaviors and may be diagnosed with OCD. Other common difficulties include learning disabilities and developmental stuttering.

Most children with TS will also feel some sort of embarrassment, social discomfort, and self-consciousness regarding their illness and tics. As children reach adolescence, they may also experience depressed mood and may be at increased risk of developing major depressive disorder.
What causes Tourette’s syndrome?
Approximately 1 in 200 children will have Tourette’s syndrome. Although the cause has not been definitely established, there is growing scientific evidence that TS is caused by a neurological illness affecting neurons (nerve cells) in different parts of the brain including but not limited to the basal ganglia. People with TS may also have a dysfunction of their neurotransmitters—the chemicals that neurons use to communicate with each other.

When it was first being studied, it was thought that Tourette’s syndrome had an autosomal-dominant inheritance pattern—that 50 percent of children would develop this illness if one of their parents had it. Scientists have since discovered that TS is probably more complicated and not based on the presence of a single gene. In fact, multiple genes have been shown to cause the symptoms of Tourette’s syndrome.

In some families, different people may have different symptoms associated with the illness. Furthermore, boys are approximately four times more likely to have Tourette’s syndrome than girls.

How is Tourette’s syndrome diagnosed?
No blood analysis, x-ray or other medical test exists to identify Tourette’s syndrome. The first step in diagnosis occurs when a young person is brought to their doctor for evaluation. Sometimes this happens when a parent is concerned about tics or another symptom of Tourette’s syndrome; other times it occurs at a regularly scheduled check-up when a person’s doctor notices these symptoms during a routine physical examination.

Many people with tics do not actually have TS. For example, transient tics of childhood is a benign condition which can be present in up to a quarter of young children. Therefore upon seeing the signs of TS, many primary care doctors (e.g., family practice doctors and pediatricians) may refer their patient to a specialist. This is not only because Tourette’s syndrome is most frequently managed by neurologists and psychiatrists, but also because it is important that any person with newly diagnosed tics have a thorough medical and neurological examination. In some people, this may include radiological tests (e.g., CT scans, MRIs), EEG (electroencephalogram), and blood tests. The specialist’s thorough evaluation will confirm a diagnosis of Tourette’s syndrome as opposed to an infection, a medication side-effect or another neurological illness as the source of the tics.

What are the benefits of seeking early treatment of Tourette’s syndrome symptoms?
When a child’s behavior is viewed as disruptive, frightening, or bizarre, it may provoke ridicule and rejection by uninformed peers, family, teachers or friends. Some people can feel scared or threatened and exclude the child from activities or interpersonal activities and relationships. A child’s difficulties in social situations may increase as he or she reaches adolescence. Therefore, it is very important for the child’s self-esteem and emotional well-being that treatment be sought as early as possible to avoid these difficulties.

Tourette’s syndrome alone does not affect the IQ of a child. Many children who have Tourette’s syndrome, however, also have learning disabilities and/or difficulties paying attention. Therefore special education is frequently needed for a child with Tourette’s syndrome. Teachers should be given factual information about the disorder and, if learning difficulties appear, the child should be referred through the school system for assessment of other learning problems.

What treatments are available for Tourette’s syndrome?
Not everyone with Tourette’s syndrome is disabled by his or her symptoms and medication may not be necessary. Relaxation techniques and behavioral therapies (often called habit-reversal training) may be very useful in the treatment of tics. Many people with Tourette’s syndrome may also benefit from psychotherapy (talking therapy) to address some of the self-esteem and self-consciousness issues associated with their illness. This can be a great resource for developing coping skills as well.

Medication treatment of Tourette’s syndrome usually focuses on decreasing the severity, frequency, and discomfort of tics for people with significant social and occupational difficulties due to their symptoms. Treatment of tics often includes medications from the antipsychotic class of drugs—referred to as dopamine-blockers or neuroleptics. These include pimozide (Orap), haloperidol (Haldol), risperidone (Risperdal), fluphenazine (Prolixin), and others. These medications carry the risk of substantial side effects—namely
movement disorders (including Tardive Dyskinesia), weight gain, and metabolic syndrome. Surgeries and other procedural treatments (e.g., botulinum toxin injection, deep brain stimulation, and transcranial magnetic stimulation) are not usually recommended and are beyond the scope of this review.

Treatment of co-existing symptoms is very important in Tourette’s syndrome to improve self-esteem and overall functioning. For example, a person with OCD may require cognitive behavioral therapy (CBT) or treatment with a medication from the selective-serotonin-reuptake-inhibitor class of medications (e.g., paroxetine [Paxil], sertraline [Zoloft], fluvoxamine [Luvox], fluoxetine [Prozac], etc.) to control their obsessions and compulsions. A person with ADHD may require treatment with stimulant medications (e.g., dexamphetamine, methylphenidate (Ritalin), etc.) or other medications (including alpha-blockers such as clonidine (Kapvay) and guanfacine (Tenex, Intuniv)) to improve their focus and control impulsive behaviors. It should be noted that stimulant medications carry the risk of increasing tic severity and therefore—as with any other medications—the pros and cons should be discussed with one’s physicians.

Through effective treatment of their tics (and other coexisting psychiatric illnesses), the overwhelming majority of people with Tourette’s syndrome can expect to see their symptoms decrease and can continue living the lives they want to live.

*NAMI Minnesota; Reviewed by Jacob L. Freedman, M.D., and Ken Duckworth, M.D., September 2012; Updated April 2017*