What Does A Kid With Tourette Syndrome Look Like?

Just Like Any Other Kid!

By Barbara M. Kelly, RN, BSN

Many of our readers have had students in their schools diagnosed with Tourette Syndrome (TS). Caring for the medical and emotional needs of these children and teenagers is a challenge for school staff, and especially for school nurses. This issue of *School Nurse News* presents information about Tourette Syndrome that will assist our readers in understanding some of the complexities of this disorder. By understanding the unique characteristics of Tourette Syndrome and by eliminating pre-existing mysteries, school nurses will be prepared to offer support and strategies that may help to minimize the symptoms and behaviors that can interfere with the education of these students.

A Professional — and Personal — Perspective

As a school nurse for over a dozen years, I have known thousands of children. I would like to tell you about three whom I know particularly well.

Case 1

D— was a middle child who was well liked by his schoolmates but struggled academically and seemed unhappy. He regaled his siblings and classmates with his mimicry, animal noises and facial and postural contortions. He often rode his bike at breakneck speed, yelling, “Look, no hands!” Not an unusual feat except that he was standing on the seat! D— began to falter academically at the end of first grade. His teacher noted that he had difficulty remembering what he had seen or heard and that he cried almost daily. He often became involved in physical altercations both at home and at school. He would kick people in the shins without provocation and then tearfully state that he “couldn’t help it.” He frequently had crying spells and stated that he “could not stop.” D—’s pediatrician gave him a clean bill of health and prescribed an antihistamine for environmental allergy symptoms (sniffling and throat clearing secondary to postnasal drip). In June, his teacher noted constant blinking; his school vision screening was normal. The boy’s mother felt that his eyes were probably irritated from the chlorine in the pool. That summer, D— became increasingly withdrawn and irritable. He could often be heard in his room making “monkey sounds” and refused to swim or play outdoors with his friends or siblings. He stated that the sun was “too bright,” the water in the pool “too cold” and the air “too hot.” He began changing his clothes several times a day because they “didn’t feel right.” He often sang and recited dialogue from television commercials in a singsong fashion. Frequently he had difficulty falling asleep and could be heard humming in a high-pitched manner. He chewed his fingernails until they bled and picked off the scabs, leaving large scars.

As summer waned, he tearfully confided to his parents that he was having "day mares," which he described as "hearing music and seeing things in my head that I can't stop that scare me." He refused to elaborate. D—'s parents became so alarmed that they asked their pediatrician for a referral to a psychiatrist and requested that the school evaluate him as well. The latter was accomplished first and "no handicapping condition" noted. Prior to seeing the psychiatrist, D— was evaluated by a pediatric neurologist, who diagnosed "probable tic disorder." An electroencephalogram was done and noted to be normal. A complete battery of neuropsychoeducational tests was administered over several weeks. Specific learning disabilities were diagnosed. A pediatric psychiatrist was also consulted, and an extensive history was obtained from the parents and the school. This process took approximately six weeks and was carried out during the summer vacation.

By late August, the team had diagnosed D— with "tic disorder, obsessive-compulsive disorder and dysthymic disorder." Specific educational accommodations were suggested and he was referred to his school district's Committee on Special Education with the recommendation that he be classified as Learning Disabled/Health Impaired. He was started on Tofranil 25 mg at bedtime for his depressive symptoms. The dosage was gradually increased to 125 mg. Copies of the private evaluations were shared with school district personnel. D—'s parents attended several meetings with school officials to determine the most appropriate setting (least restrictive environment) for their son. He was placed in a self-contained special education second grade class at an elementary school across town with eleven other students, one teacher, and a classroom aide. The school district felt that he should be classified as "multiple handicapped" with a label of emotionally disturbed, in addition to the other labels. In the new environment, D— began to make slow progress academically. His tic symptoms continued to change over time. Despite some initial unhappiness over having to leave his friends and siblings at his neighborhood elementary school, D— made a smooth transition. An Individualized Educational Plan (IEP) was developed targeting specific academic, social and behavioral goals, and parent/teacher meetings were held every few weeks. D—'s progress was communicated daily via a notebook and phone calls home. His teacher was a special education veteran with many years of experience who was eager to learn everything possible about him. After the winter vacation, D—'s diagnosis was amended to Tourette Syndrome. His mother joined a parent support group, as well as the national chapter of the Tourette Syndrome Association, and provided literature and videos to school staff. Although D— was still experiencing difficulties, the family was relieved to know that his symptoms were attributable to a disorder which was well recognized — but still misunderstood.

D—'s depressive symptoms improved as did his academic performance, and he returned to his home school for fourth grade with resource room support. In middle school, his tic symptoms became quite noticeable and he was started on Catapres (clonidine). Over several months the dosage was increased, but the drug proved ineffective and was discontinued. D— stated that he felt better off the medication. By ninth grade, D— had progressed academically, was no longer in need of special education services and was declassified. He played ice hockey, was inducted into the National Honor Society, and played guitar and sang in a rock band. In his senior year, he stopped taking antidepressant medication. He currently attends college in upstate New York and plans to teach elementary education. His tics are still present, but are not bothersome, and he matter-of-factly tells anyone who inquires that he has Tourette Syndrome. He recently wrote to his special education teachers to thank them for their support and understanding.

Case 2

A— was the youngest of three children and the only girl. Although she was a tomboy, she was afraid of the dark and always insisted that her bed face the door. She had a hard time making decisions and often missed the bus because she could not decide which shoes to wear to school. Choosing a pair the night before was no help, because they never "felt right" in the morning. A— would have to check between her toes several times each day for "sock fuzz." She daydreamed and had great difficulty mastering abstract concepts, such as time and money. In spite of memorizing her weekly spelling words and spelling them aloud at home, she failed most of her written spelling tests. Despite nightly practice, she could not seem to learn the multiplication tables, and relied heavily on her fingers or a number line. A— was unhappy about inconsequential things over which she had no control, such as the weather and the length of her hair. On several occasions she destroyed her possessions, one time pulling apart a doll and another, gouging her initials into the top of her new dresser with a nail file. She wiggled her eyebrows, flared her nostrils, and hummed. A— reported that she had a "staring problem." She expressed a need to maintain eye contact with both people and dogs until they looked away. She said that she was afraid that "something bad would happen" if she were to avert her gaze first. A— would often pull the hair on her father's or older brother's legs and then sniff her fingers. She was emotionally labile, and somewhat hyperactive, often laughing, twirling and singing or tearful and sad for no apparent reason. A— was often reprimanded for making faces in class when the teacher's back was turned, and she could not seem to stay in her seat. She hoarded useless items, such as gum wrappers, and would remake her bed many times until it was "just right."

A— was seen by a psychiatrist who diagnosed Obsessive Compulsive Disorder and Tourette Syndrome and prescribed Prozac (fluoxetine), 20 mg in the morning. It was determined that her ADD symptoms were not problematic at that time and would be monitored and treated with stimulant medication if they worsened. She was referred to a neuropsychologist to evaluate her cognitive functioning and was noted to have Attention Deficit Disorder without Hyperactivity. She received informal academic assistance three times a week and was permitted to take her spelling tests aloud or to have someone write the words as she dictated the letters. A— still had difficulty telling time, stating, "It is 5 minutes to seven thirty." She eventually mastered the multiplication table. Although her teachers commented that her "nervousness" interfered with her concentration and ability to complete timed assignments, she functioned adequately; however, she did not enjoy school. She excelled at playing the piano, had many friends and was a voracious reader. The tics persisted throughout middle school but were mild. Her obsessions and compulsions continued to interfere with her concentration and caused her great distress. She licked her eraser before correcting mistakes, causing holes in her papers. When reading, she reported that she had to coordinate her breathing with the words; if reading while eating, she would coordinate her chewing with the words. She stated that there were always “numbers or songs running through her head” which interfered with her concentration. A—’s psychiatrist increased her Prozac to 20 mg b.i.d. and her symptoms seemed to improve after several weeks. She also appeared more animated and seemed to enjoy socializing with family and friends.

Although A— was an excellent student, school remained difficult for her. Staying focused and getting organized were problems. A— would impulsively start one project or assignment before completing previous ones. Timed tests were especially difficult, because all she could think about was how much time remained. She continued to struggle with mathematics, and although she worked with a tutor several times a week, she failed the Regents examination. Despite a B in global studies, she failed that Regents test as well and attended summer school. Her psychiatrist proposed a course of Ritalin and her dosage was slowly titrated to 25 mg a day in divided doses. Her tic symptoms were not markedly increased on stimulant therapy and she reported a dramatic improvement in her attention. A— reported feeling very “focused” and enjoyed her summer school classes. She did well in the courses and eagerly anticipated the start of her junior year. As her grades improved, A— was able to resume extracurricular activities she had dropped. She started volunteering as a candy striper at the local hospital on weekends and generally seemed much happier than she had been in years. A— worried that her teachers perceived her as “stupid,” and although she knew that this wasn’t the case, she expressed her frustration at doing poorly despite extra effort and assistance. However, she has completed her freshman year at a women’s college with a 3.8 GPA. She sees her physician for medication management, and a psychotherapist several times a year.

Case 3

P— was a meticulous, bespectacled nine-year-old, the eldest of three children. He excelled in school, played piano, and loved scouting. P— frequently went to his school’s health office complaining of a stiff neck and sore feet. His mother noted that he frequently shrugged his shoulders and moved his head from side to side as though checking his glasses for a smudged or scratched lens. His toes were reddened on the plantar surfaces, but the skin was intact. P— wiggled his toes constantly, to the point that he wore holes in his socks. He stated that he “just needed to do this sometimes.” P— alarmed his scout leader several times by attempting to touch the moving bit on a power drill the group was using to build birdhouses “to see how it would feel.” On other occasions he would push the button on the garage door opener and try to run under the door before it touched him. A cautious child, these actions seemed quite out of character.

P— mimicked the way the family dog sniffed. His siblings and friends initially found this hilarious but eventually became annoyed with his incessant sniffing. He also made guttural noises in his throat, which caused him to choke when eating or drinking. P— drummed with his hands on any available surface. He did this at inappropriate times, such as in the library, at church, or when a teacher was speaking. He stated that he started wiggling his toes when one of his teachers instructed him to sit on his hands to keep him from drumming. P— was referred by his pediatrician to a neurologist for evaluation of his symptoms and was diagnosed with Tourette Syndrome. He was started on Catapres (clonidine) 0.1 mg t.i.d.; however, toward the end of fourth grade, P— became increasingly sad and withdrawn socially. He felt that he was focusing all of his energy on suppressing his tics at school and that because of this, he “could not relax.” When his parents bought him a drum set for his birthday, he started lessons and began to play in the school band. He seemed happiest when riding his bicycle and practicing drums.

P—’s tics were a source of great anguish to him throughout high school. Although they seemed quite subtle, he reported that he felt like “a social outcast.” He continued his piano and drum lessons, practicing for hours each day. P—’s obsessions and compulsions began to consume much of his time. He would perform certain rituals in order to assure himself that misfortune would not befall family members. These included sticking needles or pins into his fingertips, scratching his arms and legs with sticks, and arranging his possessions meticulously. He would check his drum set to be sure it wasn’t out of tune numerous times each evening. P— was able to articulate to his parents and doctor that he understood intellectually that his rituals did not protect others from harm. Still, he worried that if he did not perform them, an auto accident, serious illness or catastrophe would befall them. P— was started on Anafranil (clomipramine) with the dosage gradually increased, but it proved ineffective and he became increasingly depressed. Severe acne damaged his self-esteem further, but it did respond well to a 6-month course of Accutane. During this time, P— was unable to attend school and had home tutoring. A new medication, Luvox (fluvoxamine) was begun, but his symptoms persisted. Lithium was added to potentiate the effects of Luvox and P— began to respond. As his depressive and obsessive symptoms lessened he was able to return to school and decided that he would tell people that he had had mononucleosis. His lithium levels were closely monitored. Aside from a mild hand tremor, P— suffered no adverse effects from the medication. He complained about having to explain to medical personnel that he took lithium to potentiate the effects of Luvox for Tourette Syndrome, and did not suffer from bipolar disorder. On his new medication regimen, P— successfully completed high school. Over time, his lithium dosage was tapered. He still takes 150 mg of Luvox, and sees his physician every 3 months. P— graduated magna cum laude from a prestigious university. He recently toured nationally with a musical theater company and will attend graduate school in the fall.

Tourette Syndrome and Its Effects on Young People

In addition to having a diagnosis of Tourette Syndrome, each of the children presented in the previous cases was also diagnosed

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STUDENTS DIAGNOSED WITH TOURETTE SYNDROME — WHAT SCHOOL NURSES NEED TO KNOW ABOUT THIS NEUROLOGICAL DISORDER

By Linda Dychkowski, RN, MS, SNT, NCSN, Clinical Editor *School Nurse News*

What is Tourette Syndrome?

Named for Dr. George Gilles de Tourette, a French neurologist who first described this condition in 1885, Tourette Syndrome affects all ethnic groups, and both males and females. Tourette Syndrome is a neurological disorder with a strong genetic component. It is chiefly identified by tics, involuntary movements and uncontrollable vocalizations that characteristically wax and wane. A person with TS may be able to restrain tic activity temporarily (as one would try to suppress a sneeze), but eventually the tic will express itself. Tic activity lessens during states of relaxation (i.e., during sleep or while absorbed in a particular task or activity) and worsens during stressful times. The exact cause of the disorder is unknown, but it appears that genetic abnormalities adversely affect metabolism of neurotransmitters (dopamine, serotonin, and norepinephrine) in the brain. Appearing usually before the age of 18, approximately 100,000 Americans have full-blown TS, with males affected three to four times as often as females.

TS can present as mild to severe, with most of those identified falling into the mild range. Obtaining a diagnosis can be difficult due to the nature of the tics that come and go, can be suppressed, and may be absent during office visits. A diagnosis of TS is a clinical one, because it is the patient's symptoms and the family history rather than specific laboratory tests that are the definitive factors. The occurrence of both motor and phonic tics for at least a year must be present before a diagnosis can be made. Although there are no specific tests for TS, neuroimaging studies such as MRI, CT, and/or EEG may be done to rule out other conditions with similar symptoms. Although TS is chronic, it is not degenerative and does not impair intelligence. While there is no cure for the disorder, patients seem to improve with maturation and in some cases complete remission occurs following adolescence; however, other disorders (depression, anxiety attacks, and antisocial behavior) that co-exist with TS may then increase in intensity and frequency. Many of those with TS exhibit symptoms of other disorders, especially specific learning disabilities, and obsessive–compulsive, attention deficit–hyperactivity, and sleep disorders. In some cases it is these other conditions, not TS, that require treatment and medication because of their interference with daily activities.

What are the symptoms?

The first symptom of TS is usually the appearance of facial tics, such as blinking, or nose twitching and grimaces. Other motor tics, head jerking, neck stretching, foot stamping, or body twisting and bending, may also occur. Tics may be verbal when the patient vocalizes strange sounds, words or phrases, or they may manifest themselves in behaviors such as continual throat clearing, coughing, sniffing, or grunting, as well as sounds such as yelps, barks or shouts.

Tics are categorized as either simple or complex. Sudden, brief movements with a limited number of muscle groups involved are called simple tics, whereas those that are distinct, coordinated patterns of movements and involve several muscle groups are known as complex tics. Examples of simple tics are: eye blinking, shrugging, grimacing, head jerking, and yelping and sniffing. Complex tic behaviors might include: jumping, smelling objects, touching the nose, touching others, and coprolalia or echolalia (see below).

Although it is rare, some patients with severe TS may exhibit self-harming actions such as head banging, and lip and cheek biting. As previously mentioned, tic activity usually waxes and wanes, in that it increases and decreases in severity and frequency, and may also change in type or location. It is not unusual for tics to disappear for weeks or months and then to reappear suddenly. Coprolalia (uttering of obscenities) and echolalia (repeating the words of others), although the best-known symptoms, are not the most common.

The Genetics of TS

TS is a genetic disorder, with dominant inheritance, that can cause mild to severe symptoms among those in the same family. A higher incidence of milder tic disorders and obsessive–compulsive behaviors is found in families with a history of TS. Gender is also an important factor in the genetics of TS: "… tics are 2-3 times as likely to occur among the sons of a parent with TS. However, daughters are 2-3 times more likely than the sons to have obsessive compulsive traits without tics." (TSA, 2000).

Medication and TS

The majority of individuals who have been diagnosed with TS do not take medication; however, when symptoms interfere with activities some medications can help. At this time, there is no one medication available to treat all persons with TS, but there are different medications for specific symptoms. For instance, neuroleptics such as haloperidol and pimozide may help to decrease the frequency and intensity of tic activity in some patients. These drugs are usually given in small doses and are increased gradually until a therapeutic dosage is reached. Long-term use of these medications may cause tardive dyskinesia (an involuntary movement disorder). Other side effects of these drugs include: muscular rigidity, drooling, tremor, lack of facial expression, slow movement, restlessness, fatigue, depression and anxiety, weight gain, and thinking difficulties (confusion, slow mentation).

Clonidine, an antihypertensive, may also be used to treat tics. This drug appears to be more effective in decreasing motor, rather than vocal, tics. Side effects of clonidine and similar medications are: fatigue, dry mouth, irritability, dizziness, headache, and insomnia. Other drugs used to help manage tics include fluphenazine and clonazepam.

Botulinum toxin A injections (BTX) have been used to treat conditions that are characterized by abnormal muscle contractions, such as motor tics. Side effects are reported as mild and transient; they include neck weakness, dysphagia, ptosis, nausea, hypophonia, fatigue and generalized weakness. Research indicates that BTX injections, in addition to being effective and well tolerated in those with TS, also provide relief of premonitory sensations that usually precede tic occurrences (Kwak et al., 2000). Additional treatments for TS include psychotherapy, relaxation techniques, and biofeedback.

Tics and Group A Beta Streptococci

Some time ago, a student's parents came to see me regarding my concern that their child's tics seemed to be worsening. The child, a boy, had diagnoses of ADHD and obsessive–compulsive disorder (OCD), and had been medicated for many years with Ritalin. The medication seemed to be helping him, but his facial tic activity was becoming more pronounced, both at school and at home. Following my observations and recommendation, his parents brought him to his pediatrician. The next day, his parents visited me and told me their physician found that the boy was experiencing a disorder that associates increased tic activity to strep throat (he had experienced several bouts of strep throat). Although I was skeptical, I listened with an open mind and immediately began to think of other students who also might be experiencing exacerbated tic activity following such infections.

The condition described here, Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (called PANDA), occurs when antibodies attack healthy as well as infected cells and results in inflammation in the brain's basal ganglia, the area that controls movement and motor control (NIMH, 1999). Caused by an autoimmune response to infection, PANDA occurs typically in young children and is characterized by a sudden onset or exacerbation of symptoms (tics and obsessive–compulsive behaviors) that worsen over time. According to Dr. Susan Swedo and colleagues at the National Institutes of Health: "… strep infections are very common and strep-triggered neuropsychiatric disorders are quite rare, so the vast majority of children with strep infections are not at risk for developing these disorders …" The NIMH reports successful treatment of PANDA with plasma exchange (PEX) and intravenous immunoglobulin (IVIG); among subjects who receive IVIG, there was a 58 percent improvement in OCD symptoms and an improvement of 70 percent among those who received PEX.

Conclusion

Those who know and work with young people with Tourette Syndrome can only imagine what it must be like to struggle with the unpredictability of TS symptoms each and every day. When students with TS are teased by classmates, are fearful that tics will occur in view of classmates and feel isolated from them, school nurses can intervene by encouraging them to describe their frustration and together develop strategies to remedy them. School nurses can assist students in exerting some control in their lives with coping skills that address their fears and anxieties. And if further treatment is warranted, school nurses can also facilitate referrals both in and out of the school setting. Although some behaviors are involuntary and TS-related, school nurses, together with the student, parents and school staff, can work toward recognizing and managing those that are voluntary and controllable.

When TS affects a student's ability to learn, accommodations in the classroom may be needed. According to NINDS, while many of those with TS are able to function successfully in a regular classroom, "… many may have some kind of learning disability." Some TS students, for instance, have difficulty with handwriting due to compulsive handwriting or hand and arm tics, and could benefit by the use of computers and tape recorders. Others may need to have time extended during tests.

School nurses can reach out to students with TS and their families with information and support that will assist in dispelling misconceptions that affect how others view TS and the youngsters diagnosed with the syndrome. Working closely with students, teachers and families of those with Tourette Syndrome, school nurses can facilitate students' success both in school and beyond.

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National Institute of Mental Health, National Institutes of Health. *Treatments reduce strep-triggered symptoms of OCD and tics in some children* [press release]. September 30, 1999.

Tourette Syndrome Association. The Genetics of Tourette Syndrome — Whom it Affects and How it Occurs in Families [pamphlet]. Bayside, NY, Feb 2000.

Resources

Tourette Syndrome Association, Inc.
42-40 Bell Blvd.
Suite 205
Bayside, NY 11361-2820
www.tsa.-usa.org
(718) 224-2999

National Institute of Mental Health (NIMH)
6001 Executive Boulevard
Rm. 8184, MSC 9663
Bethesda, MD 20892-9663
www.nimh.nih.gov
(301) 443-4513

National Institute on Deafness and Other Communication Disorders (NIDCD)
National Institutes of Health
Bldg. 31, Rm. 3C35
Bethesda, MD 20892-2320
www.nidcd.nih.gov
(301) 496-7243

The National Institute of Neurological Disorders and Stroke (NINDS)
National Institutes of Health
Bethesda, MD 20892

NINDS is the leading supporter of research within the federal government on TS and other neurological disorders. A part of the National Institutes of Health, NINDS is responsible for supporting and conducting research on the brain and central nervous system. Contact NINDS' Brain Resources and Information Network (BRAIN) at: P.O. Box 13050, Silver Spring, Maryland 20911, (800) 352-9424

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with associated disorders that frequently accompany TS, such as learning difficulties, attentional problems, depression, self-injurious behaviors, and obsessive–compulsive symptoms. Often, the tics are less problematic for the child than these associated conditions are. Diagnosis and treatment must be based on a comprehensive history and ongoing evaluation of TS's typical waxing and waning symptoms. Because Tourette Syndrome frequently causes socially inappropriate symptoms and impacts self-esteem, peer relationships, academic performance and family functioning, a trusting, supportive and collaborative relationship between home, school, physician and other service providers is most important.

The children presented in this article were fortunate to have been correctly diagnosed within a few months to 2 years of the onset of their symptoms. As a result of public education campaigns and increased media coverage, TS is becoming a well-recognized condition; misconceptions still persist, though. For example, school personnel involved in these cases frequently inquired about environmental and family stressors such as divorce, marital discord, domestic violence, abuse, parental substance abuse, unreasonable parental expectations, mental illness, and psychic trauma as contributing or causative factors for the students' symptoms. This was counterproductive and frustrating to the families, who were coping with a wide range of emotions, including sadness, anger and guilt, as would be expected when a child is diagnosed with a chronic condition. In addition, several of D—'s teachers expressed doubt that he actually had TS, because they had never heard him "swear." The uttering of obscenities — coprolalia — is the most well known symptom of Tourette Syndrome despite the fact that it occurs fairly infrequently and is not required for diagnosis. Furthermore, the involuntary nature of the tics and the ability to suppress them are often difficult to comprehend and may be wrongly attributed to a conduct disorder, deliberate aggression, or oppositional/defiant behavior. One teacher threatened to cover D—'s mouth with masking tape unless he "stopped making noises." She stated that she had read the pamphlet on Tourette Syndrome but "didn't buy the diagnosis." A local parent support group was invaluable in assisting the parents by providing education, peer counselors, literature and advocacy services, as well as advice on how to negotiate the maze of special educational regulations and procedures to obtain appropriate interventions for students. Once the parents were informed, they could begin to inform others about the nature of their child's symptoms.

The school nurse is in an optimal position to educate school staff, support the parents and student and monitor medication side effects. The unpredictability of the symptoms with regard to severity, duration, and physical, emotional and social consequences must be considered when working with teachers, students and families. The effort required to suppress symptoms interferes with concentration, is physically and mentally taxing, and requires constant vigilance. Medication side effects, including fatigue, GI complaints, dry mouth and cognitive blunting, further complicate matters. The continued effectiveness of medications, dosage titration and side effects must be monitored over time as symptoms wax and wane. The symptoms most troublesome to the patient are targeted when pharmacological intervention is initiated — not to eliminate symptoms, but to reduce them to more tolerable levels. The school nurse can act as a liaison between school and home and provide information and resources to school personnel in order to assist them in understanding the complexities of the disorder.

Once thought to be rare, Tourette Syndrome is now estimated to affect at least 1 in every 2,500 people. Although the etiology is genetic, with vulnerability transmitted from one generation to the next, no "TS gene" has been isolated. Forms in which this vulnerability is expressed may range from full-blown TS to chronic tics and/or Obsessive Compulsive Disorder (OCD) in combination or alone, and of varying severity. Children with Tourette Syndrome require ongoing evaluation and care. Physicians who specialize in treating the condition are well versed in the latest research and medications and other appropriate interventions. In major medical centers, a team approach is often utilized to coordinate care. The team usually consists of a pediatric neurologist, a psychiatrist and a psychologist. The Tourette Syndrome Association maintains a national listing of physicians who specialize in the disorder (see Resources on page 39). Because there is no definitive diagnostic test, if parents suspect that their child has Tourette Syndrome, it is helpful to suggest that they keep a diary of symptoms and bring it along when consulting with one of these providers. Obtaining a diagnosis takes time. Other disorders may have to be ruled out. As illustrated in this article, associated behaviors may coexist; there may be symptom overlap. A thorough evaluation by a team of experts will confirm or rule out Tourette Syndrome so that appropriate treatment and intervention may begin. Finding a physician with whom parents feel comfortable and to whom the child can relate is imperative. Family therapy may be recommended, and has been extremely helpful.

Tourette Syndrome is not easy to live with, but it can be managed successfully. It is not progressive or fatal, and tic symptoms often diminish in early adulthood. Patience, empathy and a sense of humor are virtues that will serve parents well. Children with this disorder can and do lead happy and productive lives. Tourette Syndrome does not define who they are, but is rather just one facet of their identity. A combination of knowledge, excellent care, and unconditional love provides support to young people with Tourette Syndrome in their endeavors to accept and to cope with their diagnosis.

ABOUT THE AUTHOR

Barbara Kelly, RN, BSN received her associate degree in nursing from the Leinhard School of Nursing at Pace University in Pleasantville, New York in 1975. Since that time, she has worked in hospital, home care and school nursing. She recently earned her BSN from the Decker School of Nursing at Binghamton University and plans to begin her MSN studies this fall. Barbara is the mother of three children with Tourette Syndrome and has presented numerous workshops to parents, teachers, students and nursing colleagues on coping with TS.