

# Movement Disorders: Real Diseases That Deserve Real Understanding



A Series by:

*Real World Health Care*  
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Movement disorders are a group of nervous system (neurological) conditions that cause abnormal increased movements, which may be voluntary or involuntary. They can also cause reduced or slow movements.

***Movement Disorders: Real Diseases That Deserve Real Understanding*** is a recently published series of articles that spotlights the organizations and efforts dedicated to research, treatment and services for patients living with a range of Movement Disorders. Please accept this complimentary copy as our way of thanking you for your commitment to this community and advocating for healthier futures.

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# What Are Movement Disorders?

Throughout 2020, Real World Health Care will focus on [Movement Disorders](#). Movement disorders are related to the nervous system. They include a variety of neurological conditions that cause increased, abnormal movements (voluntary or involuntary) or reduced, slow movements. Some movement disorders are inherited, while others are caused by infection, medication or disease. Several movement disorders are quite rare. In this column, we will provide an overview of several movement disorders, to help you understand what they are, what causes them, and how they may be treated.

## What is Chorea?

Chorea is an abnormal involuntary movement disorder caused by overactivity of the neurotransmitter dopamine in areas of the brain that control movement. It is one of a group of neurological disorders called dyskinesias. Chorea is characterized by brief, irregular contractions that are not repetitive or rhythmic, but appear to flow from one muscle to the next. The condition occurs with athetosis, which adds twisting and writhing movements. Chorea is a primary feature of Huntington's Disease but may also occur in a variety of other conditions. It also can be induced by drugs, metabolic and endocrine disorders, and vascular incidents. A small percentage of children and adolescents who have had rheumatic fever may also get a form of chorea called Sydenham's chorea.

There is no standard treatment for chorea. Treatment and prognosis depend on the type of chorea and the associated disease. However, Sydenham's chorea is treatable and curable.

For more information on Chorea, visit the [Hereditary Disease Foundation](#).

## What is Huntington's Disease?

Huntington's Disease (HD) is an inherited disease that causes nerve cells in certain parts of the brain to die. This includes nerve cells that help to control voluntary movement. HD symptoms such as uncontrolled movements, clumsiness and balance problems typically appear in middle age, between 30 and 50, and progressively get worse. Eventually, HD can take away a person's ability to walk, talk and swallow. Changes in behavior, emotion, judgment and cognition are also common. Some people stop recognizing family members, while others are aware of their environment and can express emotions.

There is currently no cure for HD. Medicines can help manage some of HD's emotional and movement problem symptoms but cannot slow down or stop the disease. People with HD usually die within 10 to 30 years following symptom onset, most commonly from infections like pneumonia and injuries related to falls.

For more information on Huntington's Disease, visit the [Huntington's Disease Society of America](#).

## What is Parkinson's Disease?

Parkinson's Disease (PD) is a progressive neurodegenerative disease that happens when nerve cells in the

brain don't produce enough dopamine, resulting in abnormal nerve firing patterns within the brain that cause impaired movement. While some cases of PD are genetic, most do not run in families. It is thought that exposure to chemicals in the environment may play a role. PD is more common in men than in women.

Symptoms begin gradually, around age 60, and are often mild, occurring on one side of the body. Later symptoms affect both sides and, as they get worse, people experience trouble walking, talking, chewing and swallowing, or doing simple tasks. Common symptoms include:

- Trembling of hands, arms, legs, jaw and face
- Stiffness of the arms, legs and trunk
- Slowness of movement
- Poor balance and coordination

There is no cure for PD. A variety of medicines sometimes help symptoms dramatically. Surgery and deep brain stimulation can help severe cases.

For more information about Parkinson's Disease, visit the [American Parkinson Disease Association](#) and the [National Parkinson's Foundation](#).

## What is Tardive Dyskinesia?

Tardive dyskinesia (TD) is a neurological disorder that involves involuntary movements such as facial grimacing, finger movement, rocking or thrusting the pelvis, jaw swinging, repetitive chewing, rapid blinking, tongue thrusting and restlessness. It is a serious side effect that occurs when taking medicines called neuroleptics, which are antipsychotics or major tranquilizers used to treat mental health problems. TD often occurs when such drugs are taken for many months or years, but in some cases, it occurs after taking them for as little as six weeks.

After TD is diagnosed, a patient's health care provider may recommend stopping the medicine slowly or switching to another one, which may help to reverse the condition. However, even if the medicine is stopped, the involuntary movements may become permanent or even worse. Various medicines are available to treat mild and moderate TD, and deep brain stimulation may be tried for severe forms of TD.

For more information on TD, visit [Mental Health America](#) or the [National Institute of Mental Health](#).

## What is Tourette Syndrome?

Tourette Syndrome (TS) is a disorder of the nervous system. People with TS make sudden, unusual movements or sounds called tics. Common tics include throat-clearing, blinking, facial grimacing, shrugging one's shoulders, jerking one's arms and occasionally repeating words or blurting out swear words. Those with TS have little or no control over their tics, which usually start in childhood and may be worse in the early teen years. Many people eventually outgrow them, although 10-15 percent of those affected have a progressive or disabling course that lasts into adulthood.

TS is more common in boys than in girls and its cause is unknown. More than 85 percent of children diagnosed with TS also have been diagnosed with at least one additional mental, behavioral or developmental condition, most commonly attention-deficit/hyperactivity disorder (ADHD) and obsessive-compulsive disorder (OCD). No treatment is needed unless the tics interfere with everyday life. Excitement or worry can make tics worse. Calm, focused activities may make them better. Medicines and talk therapy may also help when symptoms interfere with functioning.

For more information about TS, visit the [Tourette Association of America](#).

***Resources:***

[Centers for Disease Control and Prevention](#)

[Mayo Clinic](#)

[National Institutes of Health](#)

# Navigating Cognitive Changes in Parkinson's Disease

*Editor's Note: The following has been excerpted, with permission, from [Navigating Cognitive Changes in Parkinson's Disease](#), published by The [Michael J. Fox Foundation for Parkinson's Research \(MJFF\)](#). It was written by MJFF Vice President of Medical Communications and movement disorder specialist [Rachel Dolhun, MD](#), in collaboration with Parkinson's experts, the patients and families who live with the disease, and the clinicians who care for them. [Real World Health Care](#) invites our readers to [read the free guide](#) for more information around different forms of cognitive changes, including mild cognitive impairment, Parkinson's disease dementia and dementia with Lewy bodies.*

"The goal of this guide is to encourage people with Parkinson's and their loved ones to learn more about cognitive changes and to take action—whether that's opening a discussion to lessen fear and improve care or practicing habits that boost brain health," said Dr. Dolhun. "There's a lot you can do right now if you notice or worry about cognitive changes."



Rachel Dolhun, MD, Michael J. Fox Foundation

## Parkinson's Disease and Brain Health

Not everyone with Parkinson's disease (PD) experiences cognitive issues, and when and how they occur is unique to each person. But for people and families with PD, changes in thinking and memory are among the most concerning potential symptoms and, unfortunately, also some of the least talked about.

Cognitive changes with PD often are different or more than expected with age. As you get older, it may be normal to leave your keys in the door, forget something at the grocery store or miss an occasional bill payment. But age alone doesn't usually cause a person to forget what their keys are for or how to use them, how to get to and around their usual grocery store, or how to balance the checkbook and transfer money between bank accounts.

## Tracking Cognitive Changes

When PD affects cognition, it typically impacts executive functions, such as multi-tasking, organizing and decision-making, more than memory.

How can people with PD know when they and their loved ones should be concerned about signs of cognitive changes? Consider the activities below and whether there has been a major change in many or most of them.

**Paying Attention.** Do you have trouble participating in or following the flow of group conversations? Is it harder to read books or watch movies because of difficulty following storyline or plots?

**Making Decisions and Solving Problems.** Is it nearly impossible to make decisions, such as what to do with a free afternoon? Do you make poor decisions, such as not wearing your seatbelt or spending large amounts of money you don't have? Do you have difficulty solving problems, such as how to reroute through a traffic jam or what to do about dinner when there is no food in the house?

**Remembering.** Do you forget important appointments or social engagements? Do you regularly forget who called and why? Do you lose track of the season or time of year? Do you often need reminders of how to do things that were previously second nature, such as how to turn on the television or use the computer?

**Taking Medication.** Are you able to describe which medications you take for what and when? Do you need help from your spouse or care partner to take the right medications at the right time?

**Behaving.** Have you or others noticed changes in your manner? What about your personality or mood? Are you more outspoken or withdrawn than you used to be?

**Managing Money.** If you manage the household finances, do you pay bills on time, write checks correctly and balance the checkbook? Have you started regularly buying things you can't afford or don't need?

**Working.** Do you have trouble focusing or need more time than usual to complete tasks? Is it hard to switch between tasks? Do you have difficulty multi-tasking or juggling several things at once? Are you disorganized? Is it hard to follow instructions?

If you or your loved ones notice differences in how you think, remember, act or do regular daily activities, talk with your doctor. Together, you can evaluate what's happening and figure out the best path forward.

## Boosting Brain Health

Researchers have not yet proven ways to prevent or slow cognitive changes, but current evidence suggests that what is good for your body is good for your brain:

- Exercise: Work with your doctor and physical therapist to find an exercise you enjoy, feel safe doing and will do regularly.
- Be socially active: Spending time with friends and loved ones prevents isolation and lets you practice learning new names and discussing current events.
- Eat a healthy, balanced diet: Aim for a variety of fruits and vegetables, whole grains, and more fish and poultry than red meat. (In the style of the Mediterranean diet.)
- Get involved in the community: Attend a neighborhood event or join a PD support group.
- Train your brain: Play online "brain games," do a crossword or jigsaw puzzle, learn to speak a second language or start a new hobby.
- Reduce stress: Meditate, practice mindfulness, go for daily walks, or spend time gardening or relaxing in nature.
- Sleep well: Not getting enough rest can make it harder to manage PD. Ask your doctor about ways to improve your rest and keep a regular schedule for going to bed and getting up.
- Take care of medical conditions: Diabetes, high blood pressure and high cholesterol can damage your brain's blood vessels and lead to thinking and memory problems.
- Check on mood and motivation: Depression, anxiety and apathy (lack of motivation) can cause or contribute to cognitive changes. Pay special attention to these symptoms right after being diagnosed, during a hospitalization and around the holidays.
- Drink alcohol in moderation: Too much can cause cognitive changes as well as walking and balance problems.
- Don't smoke cigarettes: Cigarette smoking is associated with Alzheimer's, stroke and other diseases that cause thinking and memory problems.

- Review your medications: Certain prescriptions and over-the-counter medications (including the PD drug trihexyphenidyl, or Artane) can cause confusion in some people.

## Starting a Dialogue

Avoiding discussions about cognitive changes can increase fear, misperception and misinformation—and lessen quality of life. It can also slow much-needed research into when these changes happen and how to treat and ultimately prevent them. By opening the conversation, people with Parkinson's and their loved ones can take steps to keep their brains healthy and recognize changes if they happen.

Patients and families are encouraged to download the free guide at [michaeljfox.org/cognitionguide](http://michaeljfox.org/cognitionguide).

The Michael J. Fox Foundation for Parkinson's Research has an ambitious goal — find a cure and go out of business. Donations go directly to the Foundation's high-impact research programs to speed better treatments and a cure for the millions of families impacted by the disease. Together, we can end Parkinson's at [MichaelJFox.org](http://MichaelJFox.org).



## Growing Up with Huntington's Disease

Next month marks Huntington's Disease (HD) Awareness Month and *Real World Health Care* is dedicating this column to an important part of the Huntington's patient community: children, teens and young adults.

"Whether youth have a parent with Huntington's or if they themselves have the early-onset form of the disease called Juvenile Huntington's Disease, they feel the impact of this rare movement disorder," said Louise Vetter, CEO, Huntington's Disease Society of America.



Louise Vetter, CEO, Huntington's Disease Society of America

### What is Juvenile Huntington's Disease?<sup>1</sup>

An estimated 41,000 people in the U.S. have HD. Juvenile HD is a less common, early-onset form of the disease that begins in childhood or adolescence. About 10 percent of people with HD are under 20, the age at which Juvenile HD is defined in terms of symptom onset.

Signs and symptoms of Juvenile HD include loss of thinking abilities, personality changes, impaired coordination and emotional problems. Children and teens with Juvenile HD often have a rapid decline in school performance as their ability to think and reason is weakened. Other common symptoms include dystonia, tremors, muscle twitching, stiffness of the leg muscles, clumsiness, slurred speech and swallowing problems.

Experiencing these symptoms can lead to feelings of anger, frustration, sadness and fear, and may also lead to aggressive behavior. Unlike in people with adult-onset HD, seizures are common.

Juvenile HD progresses rapidly once symptoms appear, and most people with Juvenile HD do not survive more than 10 to 15 years. The earlier symptoms onset, the faster the disease progresses. There is no cure for Juvenile HD, and there is no way to slow or stop the progression of the disease. Treatment is primarily supportive and focused on increasing quality of life.

"Juvenile HD is like a concentrated form of the disease in terms of its evolution," Vetter said. "Whereas HD symptoms in adults may progress over 20 years, Juvenile HD progresses within a couple of years, making it more of a crisis situation."

### Supporting Youth Impacted by Huntington's Disease

To support youth impacted by HD, the Huntington's Disease Society of America created the HDSA National Youth Alliance (NYA). NYA started in 2004 as a small group of kids who met at the HDSA Annual Convention and wanted to build a support network of peers who understand what it's like to have HD in the family. Today, NYA boasts more than 500 young men and women ages 9-29.

"The NYA is dedicated to being the last generation with HD," Vetter said. "It not only supports young people within the HD community, but also inspires the youth of HDSA to get involved in the battle against HD and be proactive in the fight."

HDSA is a classic grassroots organization with 50 chapters. Members organize local events, participate in national HDSA events, support HD advocacy and fundraising efforts, and share their experiences and observations with others in both formal and informal ways. The NYA is a unique program provided by HDSA with regional leads and mentors working with chapters to support them and youth affected by HD connect to local social workers and other resources. An e-newsletter keeps members up to date with research, volunteer initiatives and how others affected by HD are managing.

Vetter said that NYA members also are active on social media and use technology to connect one-on-one. She pointed out the NYA's [Facebook](#) and [Twitter](#) channels and noted that because suicide can be an issue within this community, NYA members and HDSA staff closely monitor social media to listen for any early cues.

## NYA Retreats and Conventions

The NYA plans regular retreats around the country to give kids impacted by HD a weekend of sharing and learning about the disease, with opportunities to ask questions in a safe environment with trained professionals.

"The retreats are free to attend and are often the first time a young person is able to meet a peer going through the same things they are," Vetter said.

The NYA also celebrates [NYA Day](#) at the [HDSA National Convention](#) each summer. Usually held the Thursday before the convention starts, the day is dedicated to education and support for members who discuss topics such as advocacy, fundraising, research and awareness for HD. This year's convention is scheduled as a virtual event for June 4-7.

## The Isolation of Juvenile HD

While only a fraction of NYA's members have Juvenile HD—most have a family member with the disease—the NYA offers those with the young-onset form of HD an important group of peers who understand and don't judge.

"Because Juvenile HD is so rare, it can be tremendously isolating, especially if the child or young adult is unable to attend school or participate in regular activities," Vetter said. "There are a lot of social factors at play, and family members need more support. They need to learn how to work with their school system and how to integrate their child in activities and community-based programs."

Families of children with Juvenile HD are encouraged to meet with school representatives to develop an Individual Education Plan, which should be reviewed frequently as the disease progresses. Parents should expect to come into contact with many people who have no experience with the disease. They may have to inform doctors, teachers and other individuals that although Juvenile HD is rare, many of the daily challenges are similar to those of children who have other disorders or disabilities.

"HD is truly a family disease, affecting parents, siblings and the extended family," Vetter concluded. "Professional counseling is important for any family member who feels overwhelmed, depressed or out of control."

### **Additional Resources:**

1-National Institutes of Health

# Answers, Acceptance and Advocacy: Growing Up with Tourette Syndrome

The symptoms started in pre-school: vocal tics including throat clearing to barking like a dog, anxiety, and difficulties with fine and gross motor skills and mental processing. Young Adam Fishbein quickly became confused and frustrated—for years, school would be “a nightmare”—and his parents became increasingly alarmed. What was happening to their bright little boy?

The search for answers would start Adam and his parents on a life-long journey of advocacy—for himself and for others with Tourette Syndrome.

“My parents were relentless and took me to about a dozen doctors and specialists over three or four years to find out what was wrong,” said Adam, now a 21-year-old graduate student majoring in public administration at American University. “I was misdiagnosed with an alphabet soup’s worth of disorders before we found a developmental pediatrician who correctly diagnosed me with Tourette and ADHD.”

Tourette Syndrome is a neurodevelopmental movement disorder that becomes evident in early childhood or adolescence. It is part of the spectrum of Tic Disorders and is characterized by motor and vocal tics. According to the Tourette Association of America, Tourette and other Tic Disorders are not rare. An estimated 1 out of every 160 children between the ages of 5-17 in the United States has Tourette.



Adam Fishbein

It is common for people with Tourette to be affected by another co-occurring condition, most typically, Attention Deficit Hyperactivity Disorder (ADHD) and Obsessive-Compulsive Disorder (OCD). There is no cure for Tourette, although various treatment options are available.

## Fighting ‘Tooth and Nail’ for Acceptance of Tourette

According to Adam, while the diagnosis gave him and his family some peace of mind—they finally knew what they were dealing with—it didn’t end his challenges, especially in school, which became “even more of a nightmare.” His behavioral issues were disruptive to other students, and he often needed to remove himself from the classroom.

His differences resulted in being mis-judged and even bullied by classmates and teachers alike. His older brother, younger sister and parents also felt the sting of isolation that comes from having a child or sibling with disabilities.

“The public school I attended didn’t know how to deal with people who had challenges like mine,” he recalled. “My parents had to fight tooth and nail to get the district to meet their obligations in terms of responding adequately to my needs.”

Adam joined the fight by working with the [Pennsylvania Tourette Syndrome Alliance \(PATSA\)](#) to organize a series of assemblies at his school to educate other students and teachers about his Tourette and how it affected him. After those assemblies, he said his classmates were more understanding. The teachers and adults, however, were not as accepting.

“I guess children are more innocent,” he said. “They haven’t had the time and experiences yet to build in biases against those who are different.”

## The Turning Point: Advocating for Tourette

Adam continued to struggle with life at his public school until fourth grade, when his parents succeeded in forcing the school district to pay for his Free and Appropriate Public Education (FAPE), a requirement of the Individuals with Disabilities Education Act (IDEA), allowing him to transfer to a small private school for students with complex learning challenges. After he began experiencing Repeated Anger Generated Episodes (RAGEs) in adolescence, Adam transferred to a therapeutic boarding school designed for kids with learning, behavioral and other disabilities like Tourette.

“As much as I didn’t want to leave home, I knew that if I didn’t, I might end up on the streets or in jail due to my Tourette RAGEs, which I couldn’t control,” he said. “During my time at boarding school, and with the help of my parents afterwards, I learned how to advocate for myself and overcome my challenges by using coping mechanisms and building a strong support system.”

Adam thrived in his new boarding school environment, where he remained for three years. Upon his return home and to a new prep school for children who learn differently in 11<sup>th</sup> grade, he became active in PATSA, the organization that helped him earlier in his life by providing guidance and materials for his elementary school assemblies. As a teen, Adam would take his involvement up a notch, becoming a junior youth mentor and then a youth mentor. He became the organization’s first youth board representative and eventually board vice president.

Adam also joined the [Tourette Association of America’s Youth Ambassador](#) program, through which he visited local schools, synagogues and community groups, delivering presentations about Tourette, much like he did in elementary school.

“The best part about being involved in PATSA and the Tourette Association’s Youth Ambassador program was meeting other kids and families dealing with Tourette and how accepting everyone was,” Adam said. “Everyone was completely comfortable to tic however they needed to without judgement. Unless you’re living with Tourette, it’s hard to truly empathize. These were ‘my people’.”

## Living with Tourette as a Young Adult

Adam ended up excelling in high school and beyond, graduating with a bachelor’s degree in Interdisciplinary Studies: Communications, Law, Economics and Government (CLEG) from American University, where he is currently completing his graduate studies in public administration.

His personal life as an advocate for himself and others with Tourette spurred him to pursue internships and professional opportunities in disability policy. As an undergraduate student, and post-graduation, Adam

joined [RespectAbility's National Leadership Fellowship](#), where he helped to cultivate a disability community resource guide for Long Beach, California, and developed a volunteer recruitment program, among other projects. He now works part-time at the National Committee for Responsive Philanthropy, which advocates to move more philanthropic resources to marginalized communities.

Thanks to a medication regimen he will be on for the rest of his life, he said many of his symptoms are now manageable.

"I'm fortunate to have an amazing roommate who isn't really bothered by my tics—or if he is bothered, he just goes to another room," he said. "I do still struggle with ADHD. I need to take breaks when sitting in a class for an hour or more or attending meetings that I'm not actively engaged in. But I don't consider those challenges as a barrier to my education or professional career."

Adam said he looks forward to launching a full-time career in public administration upon graduation, and to eventually finding a life partner to marry—someone, he said, who will be able to live with his tics and ADHD.

"At this point, my goal is to be happy and comfortable in my personal life while making a difference and effecting positive change in my professional life," he concluded.

# Tardive Dyskinesia: Shedding Light on A Serious Medication Side Effect

An estimated 44 million adults in the United States—close to 20 percent of the population—have a mental illness. While only a fraction of those adults use antipsychotic medicines to treat their illness, about one in ten who take certain forms of antipsychotics eventually develops a movement disorder called Tardive Dyskinesia (TD).

“TD isn’t widely discussed as a potential side effect of older antipsychotics as well as some of the newer atypical anti-psychotics, and many people on these medications don’t even know TD exists,” said Patrick Hendry, vice president of Peer Advocacy, Supports and Services for Mental Health America. “As a result, patients don’t always recognize the symptoms, and when they do, they don’t link them to TD. Instead, they think the TD symptoms are actually symptoms of their **underlying behavioral health condition.**”

## Who is at Risk for Tardive Dyskinesia?

TD is linked to the use of some newer atypical antipsychotics as well as older, first-generation antipsychotics, which are also called “typical” antipsychotics or “neuroleptics.” Neuroleptics affect the brain chemical dopamine and are commonly prescribed for bipolar disorder, depression, schizophrenia or schizoaffective disorder. They include:

- Chlorpromazine
- Fluphenazine
- Haloperidol
- Perphenazine
- Prochlorperazine
- Thioridazine
- Trifluoperazine

TD affects approximately half a million people in the U.S. Not everyone who takes neuroleptics will get TD. People at higher risk for the disorder include those who:

- Are older than 55
- Are female
- Are non-Caucasian
- Have taken neuroleptics for an extended amount of time
- Have a history of brain damage, dementia, alcohol or substance abuse, diabetes or HIV/AIDS



Patrick Hendry, Mental Health America

# Tardive Dyskinesia Signs and Symptoms

Unlike temporary side effects of antipsychotics—also known as extrapyramidal symptoms—TD is a permanent condition if left untreated. Signs and symptoms can appear as early as three months or as long as three years after starting a neuroleptic medication and can result in pain as well as impact everyday functioning and social interactions. Often, patients don't even realize their own signs or symptoms, which can include:

- Eye movements such as rapid blinking or twitching.
- Mouth movements such as frowning, sticking out the tongue, lip smacking, lip puckering and pursing of the lips.
- Body movements such as rapid movements of the arms, legs and torso, along with wiggling, twisting or tapping of the hands and feet.
- Facial distortion or difficulty swallowing, speaking or breathing (in severe cases).

“The general public may mistake symptoms of TD as having a developmental disability,” Hendry said. “This can lead to a sense of embarrassment, anxiety, social isolation or feeling stigmatized. It’s important for everyone to understand that TD is not linked to mental instability.”

## Treating Tardive Dyskinesia

Hendry encourages people taking neuroleptics to tell their behavioral health physician about any involuntary movement side effects as soon as they are noticed to prevent them from becoming more severe. Their physician will most likely start by administering an Abnormal Involuntary Movement Scale (AIMS) evaluation to determine if they have TD. They will also likely refer the patient to a neurologist or movement disorder specialist to confirm a TD diagnosis and rule out other movement disorders like Parkinson’s Disease.

“Patients may be reluctant to bring their symptoms to the attention of their care team,” Hendry said. “They fear that their physician may take them off of the medication they need to manage their behavioral health condition.”

Once a diagnosis of TD has been confirmed, the physician typically will adjust the patient’s medication, by stopping it completely and swapping it with another medication, or by reducing the dose to the lowest possible amount. Additional drugs (e.g., tranquilizers) may be prescribed to ease movements. If TD symptoms do not improve or the patient is not able to stop taking the medicine that causes TD, the physician may prescribe new medications to adjust the levels of dopamine in the brain.

“Signs of TD may remain even after stopping the medication that caused them in the first place,” Hendry cautioned.

## Support for Patients with Tardive Dyskinesia

Mental Health America supports people with TD through education and advocacy work. Part of that advocacy work focuses on encouraging patients and their loved ones to request diagnostic criteria for medication approval if they are denied access to newer treatments that eliminate or reduce TD symptoms.

Hendry, whose own TD was undiagnosed for some time until his wife brought symptoms to his attention, speaks about TD to groups around the country and has organized focus groups of others with TD to share stories and strategies for living with the condition.

“Having TD can be a lonely experience,” Hendry said. “A sense of community becomes increasingly important.”

Mental Health America’s 250 local affiliates—many of them community mental health centers—also conduct outreach to both patients and providers, particularly around the importance of annual TD screening for patients on old-line antipsychotics.

“We want to make sure that providers stay updated about the potential ramifications and lesser-known side effects of these antipsychotics so they, and their patients, can share in decision-making around behavioral health treatments,” Hendry added. “When patients are well informed and participate fully in treatment decisions, they have better outcomes.”



# Tourette & Comprehensive Behavioral Intervention for Tics

This week on Real World Health Care, we continue our series on Movement Disorders with a conversation with Matthew Capriotti, PhD, associate professor of Psychology at San Jose State University. Dr. Capriotti, who collaborates actively with the Tourette Association of America (TAA) to conduct research, advocacy, and educational events, has spent the last decade conducting research on behavioral treatments for Tourette Syndrome as well as providing behavior-based clinical services to those with Tourette, other tic disorders and obsessive-compulsive disorders.

We spoke about the role of Comprehensive Behavioral Intervention for Tics (CBIT) and his work with Treating Tourette Together, a collaboration between the TAA, the Patient-Center Outcomes Research Institute and leading behavioral science researchers.

## First Line Treatment for Tourette

**Real World Health Care:** Why is behavioral therapy an important strategy for people with Tourette?

**Matthew Capriotti:** The American Academy of Neurology recommends CBIT or behavioral therapy as a first line treatment for managing the symptoms of Tourette. These recommendations are based on large-scale, well controlled studies showing behavioral therapy is both effective and safe for children and adults. We also know it's an option families desire.



Matthew Capriotti, PhD, San Jose State University

When Tourette is diagnosed, usually around the ages of 5 to 8, some families may take a wait-and-see approach to tics, which tend to peak in severity in later childhood or early adolescence. Or perhaps they will try medication to manage symptoms. Those strategies may be helpful, but they give the child or their family a limited amount of agency in terms of actively managing tics.

CBIT gives both patients and their families specific skills they can implement to proactively manage tics in the moment, when they happen.

It is important to acknowledge that CBIT is not a cure for Tourette. The goal is not to eliminate tics completely; that is not realistic for any therapy. Instead, the goal is to teach skills that allow those with Tourette to manage tics on their terms, so they have fewer problems and can live the lives they want.

# How it Works

**RWHC:** What can someone with Tourette expect when receiving CBIT?

**MC:** CBIT is typically conducted weekly, for about 10 weeks, although that can vary quite a bit based on the patient and their needs. The therapist will meet with the patient and their family and discuss how their tics have been over the last week, but the majority of the session focuses on exercises and skills to manage tics. Those skills involve what we call “competing responses,” which are physical postures or movements designed to interrupt a tic sequence or stop a tic from occurring when the urge arises.

During the exercise and skill-building portion of a session, the therapist may start by having a general conversation with the patient about something the patient is interested or involved in—school, sports, movies—or playing a game with the patient to mimic normal daily activities. During the conversation or game, the patient will practice detecting tics and implementing the competing response.

If the patient mentions issues with an arm-raising tic, for example, the competing response may be for the patient to put his hand on his thigh and his elbow against his body. We’ll practice this over and over again, with the therapist acting as a coach.

We’ll also work closely with the patient’s parents so they can learn the skills needed to help with the coaching, by praising their child when a competing response skill is used and giving them gentle reminders if they notice their child forgetting.

We also help the patient and their family identify situations in which tics are more frequent and teach them problem-solving skills for managing or changing those situations.

As therapists, our goal is not to be the “tic police.” We don’t mandate how often these skills are used. We also encourage parents to refrain from tic policing, in favor of supporting their child in more empowering ways. Instead, we work together with the patient and their family to establish individual goals, whether that’s using their skills 35 percent of the time, or 95 percent of the time. The key here is the skills themselves, and how they can be used in day-to-day life in ways that work for them and produce the results they want.

## Treating Tourette Together

**RWHC:** How is Treating Tourette Together helping to advance CBIT and other behavioral therapies?

**MC:** We held a summit last summer to bring together a variety of stakeholders and set an agenda for the next generation of research. Traditional clinical research is very investigator-driven, and we wanted the entire Tourette community—patients, providers, and families—to also have a voice in determining priorities for research that would be useful to them. The summit identified four key priority research areas, which I’ll describe in no particular order.

One priority is expanding access to CBIT. Unfortunately, many with Tourette don’t have access to treatment because there aren’t any providers in their area, or because local providers don’t take their insurance, which creates a cost barrier to care. Telehealth, which seems to be to be just as effective as in-person CBIT in small studies, may play a role here, but we need larger-scale studies to determine its widespread feasibility.

A second research priority addresses how to improve CBIT and make it more efficient. We know CBIT works well and over half of those participating in it receive life-changing benefit. But that means that about half don’t get meaningful benefit or any benefit at all. We want to make the response rate even higher.

Third, because people with Tourette often have co-morbidities like ADHD and OCD, we need to better understand how CBIT fits within other care patients receive from other providers. When is the best time to receive CBIT? How does CBIT interact with medication and how should the two be sequenced? Where do we start?

Fourth—and this is an area we probably wouldn't have identified without a cross-section of stakeholders—what other outcomes can we focus on besides tic reduction? How can behavioral health treatments improve a patient's sense of self and reduce their stress? How can it help them be more productive in class, learn to drive more safely, or have healthier relationships?

## CBIT: Keys to Success

**RWHC:** How can patients and their families approach CBIT to help ensure the best possible outcomes?

**MC:** Current evidence suggests that CBIT works well with youth ages 9-17 and adults ages 18-65. It has also been shown to work with patients who only have tics as well as those with other co-existing conditions like ADHD and OCD. The type of tics and their severity also don't appear to have an impact on outcomes.

Dr. Shannon Bennett, I and a group of colleagues published a small study last year that looked at modifying CBIT to make it developmentally appropriate for younger children, ages 4-9. The results from that study looked promising, in that the patients in the study got better over the course of treatment and stayed better a year following treatment. However, larger, more well-controlled studies are needed in this area.

One thing all these studies have shown is that for treatment to work well, the patient and their family must actively want to manage their tics. They need to be willing to do the work and must be committed to weekly therapy sessions. Sometimes, there is a disconnect here between what the parents want and what the child wants. If the child isn't ready or isn't too worried about the impact of tics on his or her life, it's not as effective. We never want to start treatment by forcing a child to do the work.

I would encourage parents to do some extra legwork to make sure they have a provider who really understands Tourette and can help them navigate the continuum of care their child needs. Fortunately, the earlier stigma around receiving treatment is eroding, which is gratifying to see. We still have a lot of work to do to improve CBIT and make it more available, as well as to keep getting accurate information about Tourette Syndrome and CBIT out there to the public.

## About the Tourette Association of America

Founded in 1972, the Tourette Association of America (TAA) is dedicated to making life better for all individuals affected by Tourette Syndrome and Tic Disorders. As the only national organization serving this community, the TAA works to raise awareness, advance research, and provide ongoing support to patients and families. To support this, the TAA directs a network of 31 Chapters, 83 support groups and recognizes 20 Centers of Excellence across the country. For more information on Behavioral Therapies, Tourette Syndrome and Tic Disorders visit [tourette.org](http://tourette.org).

# Parkinson's Foundation Partners with VA to Help Veterans Living with Parkinson's Disease

The U.S. Department of Veterans Affairs (VA) and the [Parkinson's Foundation](#) have teamed up to improve the health, well-being and quality of life of [veterans living with Parkinson's disease](#). The collaboration is designed to ensure that veterans diagnosed with Parkinson's have access to the information and resources they need to better manage their health.

According to the Parkinson's Foundation, about 50 percent of veterans are 65 or older, an age that puts them at greater statistical risk for Parkinson's, which typically presents symptoms at age 50 or older. Moreover, many veterans have been exposed to environmental risks and traumatic brain injury, both of which carry a correlation with Parkinson's. Of the approximately 1 million people in the U.S. with Parkinson's, about 110,000 are veterans.

The VA/Parkinson's Foundation partnership has three primary program goals:

- Increase access to Parkinson's information, resources and providers.
- Educate both veterans and providers on Parkinson's management and best practices.
- Help veterans navigate Parkinson's-related health and social services.

## Closing the Gaps for Veterans with Parkinson's Disease

"We've found that veterans are not always aware of the Parkinson's-related resources and services available through the VA, which leads to them being underserved in terms of health care access," explained Veronica "Ronnie" Todaro, executive vice president and chief operating officer, Parkinson's Foundation. "Our partnership with the VA is designed to improve our understanding of priorities so we can fill those gaps. We want to make sure Parkinson's is identified early so that people can engage with providers who have experience with the disease as well as have the information they need to best manage their PD."

Todaro suggested that veterans and their loved ones can start by visiting the VA's online resource to learn more about their [Parkinson's Disease Research, Education and Clinical Centers](#) (PADRECCs), which are located around the country and are staffed by internationally known movement disorder specialists, neurosurgeons,



Ronnie Todaro, COO, Parkinson's Foundation

psychiatrists, researchers, social workers and other Parkinson's experts. PADRECCs can assist veterans in effectively managing Parkinson's and other movement disorders by way of VA pharmacy benefits; physical, occupational and speech therapies; medical

equipment; surgical services; and other valuable resources. The Parkinson's Foundation also has [information for veterans](#) on its website including targeted resources for the [newly diagnosed](#) and tools and resources for care partners.

"Multi-disciplinary care is critically important to people with Parkinson's and is a priority of both the VA and the Parkinson's Foundation," Todaro said.

## Managing Parkinson's Care Costs

The economic burden of Parkinson's disease is nearly \$52 billion every year, according to a [recent study](#). Todaro noted that the Parkinson's Foundation partnership with the VA will help to address the cost impact on veterans and their families by ensuring those with the disease are aware of various resources and benefits available.

"Veterans need to be aware of all of their benefits, including those that come from having a service-related disability," she concluded. "As a Foundation, we are committed to addressing issues relating to cost, including non-medical costs such as missed work, lost wages, forced early retirement and family caregiver time."

The Parkinson's Foundation makes life better for people with Parkinson's disease by improving care and advancing research toward a cure. For more information, visit [www.Parkinson.org](http://www.Parkinson.org) or call the free Helpline at 1-800-4PD-INFO (473-4636).