AMERICAN PARKINSON DISEASE ASSOCIATION
MISSOURI CHAPTER
Strength in optimism. Hope in progress.
May/June 2023

UNTWISTING DYSTONIA IN PARKINSON DISEASE

It is estimated that over one-third of people with Parkinson disease (PD) experience dystonia.

Dystonia is a sustained or intermittent muscular contraction frequently accompanied by abnormal movements, postures, or both. People with PD and dystonia often describe uncontrollable, prolonged muscle tension, spasms, or cramp-like sensations that are occasionally painful. Dystonia can affect any body region in PD, most commonly a foot turning in, flexion of the toes, a neck tilt, elevation of a shoulder, or difficulty opening the eyes. The symptoms usually begin in one body region — leg, neck, face, jaw, arm — and sometimes spread to other regions over time. Exertion (e.g., walking) may temporarily trigger or worsen dystonia, but symptoms can also occur at rest. Severity varies from person to person.

In those with young-onset PD, dystonia symptoms may occur before development of classic motor symptoms such as rest tremor, bradykinesia or rigidity. Most often, dystonia occurs after initiating medications to treat motor symptoms of PD. A variety of PD treatment-related dystonia patterns may occur when: 1) medication wears off, 2) medication reaches peak dose, or 3) both medication kicks in and wears off, or "diphasic dyskinesia." **Dystonia occurring when medication wears off** most commonly occurs in the morning, affects the feet, and is associated with pain. **Peak-dose dystonia** typically involves the neck, face and upper limbs while **diphasic dyskinesia** tends to involve the legs, both without pain.

Successful treatment first involves optimizing the dose and timing of medications used to treat PD motor symptoms. Muscle relaxers and pain relievers may also be considered. Botulinum toxin can provide significant relief for months after injected into affected muscles, but this requires frequent doctor visits and careful assessment of potential side effects. Physical and occupational therapy are sometimes helpful, and

UNTWISTING DYSTONIA (continued)

some report beneficial effects from acupuncture and massage therapy although rigorous studies evaluating these treatments remain limited. Deep brain stimulation (DBS) for PD may either treat or cause symptoms of dystonia depending on stimulation settings. Patients with DBS and dystonia should discuss this with their DBS programming team. One of the most important aspects of successfully treating dystonia in PD relates to a clear understanding of the timing of dystonia in relation to taking PD medications. Journaling the presence or absence of dystonia in relation to medication dosing will help you and your provider optimize dystonia treatment in PD.

Dystonia does not occur exclusively in people with PD. It frequently occurs as an "isolated" syndrome where dystonia is the only neurological sign, or "combined" with other neurological features accompanying many other neurological disorders (stroke, Huntington disease, etc.) The cause of dystonia remains unknown although research suggests it relates to abnormal communication between brain regions. Dystonia is of high interest to researchers studying PD since both disorders relate to abnormal dopamine signaling in the basal ganglia. Ongoing research strives to determine genetic, environmental and brain mechanisms that contribute to dystonia, providing hope to improve treatment. For those interested in learning more about dystonia, please refer to the Dystonia Medical Research Foundation (https://dystonia-foundation.org).

Dr. Norris is the Head of Movement Disorders at Washington University School of Medicine. He evaluates and treats patients with Parkinson disease, dystonia and other movement disorders. He leads a research laboratory geared at better understanding dystonia and related disorders.

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Contact Dominique Woodhouse
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or 618-401-2328

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mjhessler@wustl.edu
or 314-286-1478

Memory Intervention for PD Study
Contact Tasha Doty
tdoty@wustl.edu
or 785-865-8943

MULTI-TASKING WITH PD

Walking and talking at the same time or doing more than one thing at a time is a common activity for many people. For example:

- **Exercise:** Walking and talking can be a part of a regular exercise routine, such as going for a walk with a friend or participating in a group fitness class.
- **Socializing:** Walking and talking can also be a way to socialize and catch up with friends or family members, whether it is taking a stroll through the park or walking around the neighborhood.
- **Medical appointments:** People may have to walk and talk at the same time during medical appointments, such as when discussing symptoms with their doctors or nurses.
- **Daily tasks:** Walking and talking may also be necessary for completing daily tasks, such as taking a phone call while carrying groceries home from the store, or walking to the mailbox while greeting the mail carrier, or conversing with a neighbor while walking their dog.

These daily activities may seem straightforward for many of us, but they require our brains to do many complicated things all at the same time. Walking requires that our brains attend to motor control, balance, movement planning, and our environment, all of which involve multiple areas of the brain working together. Additionally, our brains have to continually update each of these so that our movement continues to adhere to our plan and fit with any changes in our environment.

Meanwhile, talking requires multiple steps from thinking what to say to activating the speech muscles. Before we can speak, we must conceptualize what we want to say by retrieving information from memory. Our brains formulate this message into words and phrases by selecting appropriate words. The movements of the vocal folds, the mouth, tongue, and the lips must be coordinated to articulate the speech sounds. Similar to walking, we adjust our speech in real-time to ensure our messages are being conveyed accurately.

Parkinson's disease (PD) disrupts an individual's ability to perform tasks that were once done automatically, forcing them to think more about what they are doing and how they are doing it. Notably, the once automatic tasks that are commonly impacted by PD include walking, talking, and many other tasks in daily life.

Often the impact of PD on these tasks is minimal or hardly noticeable at the early stages of the disease, however, when individuals attempt to do these in challenging or complex situations, they find that things are not as automatic as they used to be. It is not uncommon that many patients find that walking requires more thought or that speaking requires more effort.

While there is no known method that will completely reverse this challenge, there are things that can be done to minimize this impact.

- **Be physically active.** Physical activity helps to maintain better control of walking, balance, and movement.
- **Be socially engaged.** Talking to family, friends, and people in community not only boosts the speech circuits in the brain but also reduces isolation and loneliness.
- **Make time to be cognitively challenged.** Time spent thinking in new or different ways encourages the brain to maintain flexibility, like jigsaw puzzles, sudoku, learning something new, or using technology in a new way.
- **Practice.** If you want to be better at doing more than one thing at a time, it takes practice. To practice this optimally you should do activities that are sufficiently challenging together in that you find it hard but doable to maintain your walking speed or talking. A rehabilitation professional can help you practice these activities safely.

Ideas for practice during walking:

- Name as many animals as you can
- Name words that begin with the letter "T"
- Recall the names and birthdates of family members or friends
- Explain how you do something (like changing the oil in a car, how you plant flowers, describing a recipe)
- Hold a conversation

If walking is hard, we suggest doing these things while standing still, standing up and sitting down, or marching in place. Any combination of thinking, speaking, and moving could be used to create the right kind of challenge. This could even include doing a crossword puzzle while maintaining a conversation.

Our research shows that individuals with better ability to do two things at once are less likely to experience rapid progression of their symptoms. We are conducting research to help us design effective therapy recommendations for PD and improve the ability to meet the daily demands of safely doing more than one thing at a time.

Dr. Yi-Fang Chiu, PhD, CCC-SLP, is an Associate Professor in the Department of Speech, Language & Hearing Sciences at Saint Louis University where she studies improving speech communication skills in Parkinson's disease.

Dr. Jason Longhurst, PT, DPT, PhD is an Assistant Professor in the Department of Physical Therapy and Athletic Training at Saint Louis University where he studies how Parkinson's disease impacts meaningful daily life participation.

IN-PERSON EXERCISE CLASS SCHEDULE

Contact individual location to register. For more information please call 636.778.3377 or apdamo@apdaparkinson.org

MISSOURI CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	LEVEL	CLASS
Chesterfield ADPA Office	Tuesday	10:00am	Jen Berger	Level 3	Circuit Training
	Tuesday	11:00am	Jen Berger	Level 2	Strength and Cardio
	Wednesday	10:00am	Michelle Valenti	Level 2	Movement Training
	Wednesday	11:00am	Michelle Valenti	Level 1	Seated Exercise
	Thursday	11:00am	Craig Miller	Level 1 & 2	Tai Chi
	NEW Thursday	12:00pm	Jen Berger	Level 3	Parkinson's Boxing
	Thursday	1:00pm	Michelle Valenti	Level 2	Strength and Cardio
	Friday	10:00am	Craig Miller	Level 1	Tai Chi and Meditation
	Friday	11:15am	Craig Miller	Level 2	Tai Chi
Chesterfield YMCA	Mon/Wed	12:30pm	Michelle Valenti	All Levels	Parkinson's Pedalers
Jefferson Co. YMCA	Mon/Thurs	10:00am	Linda Thompson	All Levels	Parkinson's Exercise
Kirkwood YMCA	Monday	11:30am	Frank Tucci	Levels 1 & 2	Parkinson's Exercise
Maryland Hts. YMCA	Tuesday	11:00am	Joan Paul	Level 2	Exercise for Parkinson's
South County YMCA	Tues/Thur	3:30pm	Peggy Higgins	Levels 1 & 2	Exercise for Parkinson's
St. Louis City Stephen A Orthwein Ctr.	Thursday	12:00pm	Annie Morrow	Level 1	Interval Training
	Friday	2:00pm	Mike Scheller	Levels 1 & 2	Fit and Fun
St. Peters BJC	Thursday	11:00am	Vicky Frazier	Level 1 & 2	Strength and Cardio
Ste. Genevieve	Thursday	11:00	Becky Baumann	Level 2	Parkinson's Exercise
Washington YMCA	Mon/Wed	1:00pm	Lynn/Kindall/Linda	Level 1 & 2	Parkinson's Exercise
ZOOM	Tuesday	9:00am	Jen Berger	Level 1	Seated Exercise
ZOOM	Thursday	2:00pm	Michelle Valenti	Level 1	Seated Exercise

ILLINOIS CLASS SCHEDULE

LOCATION	DAY	TIME	LEADER	CLASS
Breese/Clinton Co. YMCA	Tues/Thurs	12:30pm	Jack S.	Exercise for Parkinson's
Champaign YMCA	Monday	1:00pm	Jessica B.	Strength & Balance
	Tuesday	1:00pm	Lindsey R	Functional Chair Fitness
	Wednesday	1:00pm	Jessica B	Seated Yoga
	Thursday	1:00pm	Tesha S.	Functional Chair Fitness
	Friday	1:00pm	Lindsey R.	Standing Functional Fitness
Decatur YMCA	Tues/Thurs	9:00am	Michelle P. & Margie	Pedaling for Parkinson's
Edwardsville YMCA	Tues/Thurs	11:00am	Mary T. & Lara C.	Exercise for Parkinson's
Highland Korte Rec Ctr.	M/W/Th	11:00am	Hilary Held	Cycle and Strength
O'Fallon YMCA	Tues/Thurs	12:00pm	Victoria W. & Stefanie M.	Exercise for Parkinson's
Quincy YMCA	Tues/Fri	10:30am	Cathy Schluckebier	Fit to Fight PD Boxing
Springfield First Presb. Church	Tues/Thurs	1:30pm	Eve Fischberg	The Joy of Movement
VIRTUAL	Wednesday	10:30am		

SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email apdamo@apdaparkinson.org

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Ballwin	4th Tuesday	2:30pm	Chaplain Carla Schmidt	Meramec Bluffs Care Center
Cape Girardeau	2nd Monday	5:30pm	Jayanti Ray	Cape Girardeau Library
NEW! Chesterfield	3rd Thursday	2:00pm	Michele Dain	Friendship Village Chesterfield
NEW! Chesterfield	2nd Tuesday	1:00pm		APDA Office - Newly Diagnosed
Chesterfield Caregivers	2nd Monday	10:30am	Lynda W. & Jay B.	APDA Office
NEW! Florissant	1st Tuesday	10:00am	Sharon Wells	Garden Villas North
NEW! Kansas City	2nd Wednesday	4:00pm	Stephanie Valente	Johnson Co Rehab Hospital
NEW! Olivette	3rd Tuesday	11:00am	Diana Tucker	Private Home Care
Rolla	3rd Tuesday	2:30pm	Julie Riggs	Phelps Health Cancer Inst.
South County	4th Wednesday	10:00am	Melissa Mann	Cedarhurst of Tesson Heights
Ste. Genevieve	2nd Wednesday	10:00am	Teddy R. & Maria R.	Ste. Gen. Community Center
St. Peters	1st Tuesday	1:00pm	Amanda S. & Whitney M.	Spencer Road Library
Washington	2nd Monday	3:00pm	Teresa V. & Chris H.	Washington Public Library
VIRTUAL	3rd Monday	1:00pm	Kathy Schroeder	St. Louis Caregivers **ONLY**
VIRTUAL	4th Tuesday	6:30pm	Terri Hosto	PD Virtual
VIRTUAL	Every Thursday	6:00pm	Karen F. & Mike M.	Young Onset **ONLY**

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	LEADER	MEETING SITE
Alton	2nd Wednesday	1:00pm	Dustin Heiser	SSP Main Building The Meeting Room
	2nd Tuesday	2:00pm	Dustin Heiser	SSP Wellness Center **CarePartners Only**
Belleville	3rd Monday	1:30pm	Jodi Gardner	SW Illinois College's Programs and Services for Older Persons
	3rd Tuesday	11:00am	Jodi Gardner	Belleville Health and Sport Center **Caregivers ONLY**
Carbondale	1st Wednesday	1:00pm	Gala Lockwood	Prairie Living at Chautauqua
Champaign	Every Monday	10:00am	Dave M. & Diane K.	Savoy United Methodist Church
Decatur	3rd Thursday	1:30pm	John Kileen	Westminister Presbyterian Church
Edwardsville	1st Tuesday	2:00pm	Pam P. & Sarah H.	Edwardsville YMCA
Greenville	2nd Tuesday	1:00pm	Robbie Mueth	Bond County Senior Citizens
Highland	4th Tuesday	2:00pm	Kayla Deerhake	St. Joseph Hospital Sullivan Conference Room
VIRTUAL	1st Wednesday	1:00pm	Jim & Fran Ringle	PD Virtual Jacksonville
Quincy	2nd Saturday	10:00am	Terri & Dave May	Quincy Public Library

POSTURE PROBLEMS IN PARKINSON'S DISEASE

Posture and PD

A well-established but poorly understood clinical feature of Parkinson's disease (PD) is difficulty with posture. Most people with PD exhibit some degree of stooped posture. A smaller group of people with PD have more pronounced problems with posture. They might walk with an extreme bend at the neck, shoulders, or waist. They might walk with a prominent tilt of the trunk. This article will explore these troubling problems, discuss why they might happen in PD, and although there's no easy or clear fix, offer some potential solutions.

As always, please bring any concerns or changes, including posture issues, to the attention of your healthcare team. The sooner you address them, the sooner you can work together to find answers and hopefully mitigate the issues you're experiencing.

Stooped posture

People with PD characteristically walk and even sit in a stooped posture, with their shoulders hunched forward. This tends to tip a person's center of gravity forward and can contribute to falls. A pronounced manifestation of this may result in a festinating gait in which a person takes small, rapid steps, which can resemble running, in an attempt to "catch up" with their center of gravity which is propelled forward due to stooped posture.

Counteracting the tendency of the person with Parkinson's to sit and walk with a stooped posture is often a constant struggle. The brain in someone with PD directs the body to assume a small amount of space and to move in small ways. To offset this, physical therapy techniques can be employed which emphasize a larger stance, bigger movements, and an erect posture. These techniques can help stabilize the gait and remind the brain to "undo" the stoop.

Dropped head syndrome and camptocormia

Approximately 5-10% of people with PD have a more pronounced problem with their posture. One potential difficulty is a pronounced forward flexion of their head, called dropped head syndrome (DHS). Another, is a pronounced flexion of their entire trunk, called camptocormia or bent spine syndrome (often defined as a greater than 45-degree flexion of the spine). These two conditions have many causes besides PD including other neurodegenerative diseases such as the Parkinson plus syndrome, and amyotrophic lateral sclerosis (ALS), and muscle or nerve diseases such as chronic inflammatory demyelinating polyneuropathy (CIDP).

Typically, in dropped head syndrome and camptocormia, the forward flexion is present with sitting and increases with walking. When lying down on the back however, the neck and trunk can mostly or completely straighten out. This distinguishes it from a fixed posture of the neck or back called kyphosis or kyphoscoliosis, which does not straighten out when lying on the back. Kyphosis is common as people age and is not related to PD. It can be caused by osteoporosis, leading to compression fractures of the spine,

arthritic changes in the spine, and degenerative disc disease. Both kyphosis and camptocormia can co-exist in one person, which complicates the diagnosis. Both are also more common in women than men.

Regardless of the cause, having a flexed trunk and/or head can be very problematic, leading to significant disability including difficulty eating, swallowing, and socializing. The flexion can limit looking upwards and can contribute to poor control of saliva as well. It can make standing up and walking more difficult and can also cause breathing problems by restricting the amount the lungs can expand. Pain is often a feature as well.

Pisa syndrome

Another common postural abnormality in PD is lateral bending of the trunk (often defined as a greater than 10-15 degree bend) with a tendency to lean to one side, known as the Pisa syndrome. Despite the fact that most people have symptoms of PD that are more prominent on one side of the body, PD laterality has not been shown to correlate with the laterality of Pisa syndrome. A person with Pisa syndrome may lean toward or away from their more parkinsonian side.

Many of the clinical features of Pisa syndrome are similar to that of dropped head syndrome and camptocormia. Similar to camptocormia, the lateral flexion is most pronounced with walking and is not present when lying down. Also similar to camptocormia, this syndrome can be a feature of MSA.

It has been suggested that dysfunction of the vestibular system (the part of the nervous system, based in the inner ear that contributes to balance control), as well as dysfunction of the proprioceptive system (the part of the nervous system that senses the body's position in space), may contribute to lateral leaning seen in PD. It must be noted that it is possible to see both lateral flexion and forward flexion of the trunk in the same person. Often, the lateral lean develops slowly, to the point that the person may not be aware that the trunk is not straight.

Potential treatments

Various treatment options have been tried to correct these abnormal postures in PD. However, the treatments reported in the literature are typically of only small numbers of patients and results are mixed. The following show some promise in helping those with postural abnormalities in PD:

- **Physical therapy techniques directed at postural abnormalities:** A number of techniques have been studied including back muscle strengthening exercises, postural re-education, kinesio-taping of the back muscles, proprioceptive training and stimulation, as well as stretching exercises.
- **Use of a high frame walker with forearm support**
- **Increase of levodopa:** In a small subset of people, truncal abnormalities may worsen at the end of a levodopa dose and may respond well to an increase in levodopa.
- **Withdrawal or adjustment of the medication** thought to have initiated the postural abnormality
- **Botulinum toxin injections** of muscles of the trunk, back or abdomen found to be overactive
- **Deep brain stimulation** (this has been tried infrequently and may be beneficial in select situations)
- As with many issues, it makes sense to start addressing abnormal posture when it is mild. Physical therapy directed at correcting a mildly abnormal posture, for example, is more likely to reap benefits than when the problem is more severe.

Despite best efforts however, postural problems may worsen and may not be helped sufficiently by the treatment options listed here. More research needs to be done to determine the best way to improve these troubling symptoms.

Used with permission from Dr. Rebecca Gilbert's blog, A Closer Look. Dr. Gilbert is the Chief Medical Officer of the APDA.

We will be known forever by the tracks we leave...

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AMERICAN PARKINSON DISEASE ASSOCIATION

Please join us on **Saturday, October 7, 2023** at the Logan University Athletic Field for this year's APDA Missouri Optimism Walk.

Lace up your sneakers and step up to help us put an end to Parkinson's disease!

APDA Missouri Chapter

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