



# AMERICAN PARKINSON DISEASE ASSOCIATION

## MISSOURI CHAPTER NEWSLETTER

February/  
March 2024

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## LIVING IN A SMART HOME

*By Sydney Marshman OTD, OTR/L, Program Consultant, Iowa APDA Chapter*

It's essential to ensure that your home is a comfortable and safe space. This article focuses on simple, yet impactful indoor modifications tailored to support individuals living with Parkinson's disease (PD). By emphasizing changes that enhance safety and ease of movement, these adjustments aim to create a smart home environment that fosters independence. Symptoms like tremors, stiffness, and balance issues, can increase the risk of falls and make daily tasks challenging. Implementing slight modifications within the home can significantly enhance safety and ease of living with PD.

### Flooring and Lighting

Installing non-slip flooring throughout the house, especially in high-risk areas like bathrooms and kitchens, can reduce the chances of slipping. Bright and evenly distributed lighting helps improve visibility, aiding movement and preventing accidental falls. It's important to consider lighting during both day and nighttime, ensuring pathways during midnight bathroom trips are well lit. Night lights now come in various shapes and styles, offering features like rechargeable batteries, removability, and motion sensors.

### Furniture Selection & Arrangement

As the winter months have you cozied up in your favorite chair, you might start noticing it's asking for a bit more TLC – perhaps a fluff-up or a brand-new replacement! Furniture selection is equally important as furniture arrangement. Furniture should not only be comfortable, but also stationary, firm and an appropriate height to easily sit to stand from. Chairs with armrests are typically preferred as armrests can assist with moving from sitting to standing. Furniture should be arranged to create clear pathways. This means removing unnecessary obstacles and reducing the number of sharp corners on coffee tables and large pieces. This process minimizes the risk of tripping and accidental injury. We'll talk about technology a bit later, but consider cord management and how to remove cords from walkways.



# LIVING IN A SMART HOME (continued)

## Bathroom Modifications

I think we're familiar with standard bathroom recommendations to reduce fall risk – tall toilets, grab bars, a shower seat for additional support. There are many other solutions that may improve bathroom safety and independence. Non-slip strips and non-slip paint that adheres to the shower floor reduces the need to fuss with a nonslip shower mat. A bendable, long handled shower brush might help with hard to reach places. A security or transfer pole can be easily installed in places that may not accommodate a traditional grab bar.



## Kitchen Adjustments

The kitchen often functions as the heart of our home particularly during the holiday season and winter months. It's a great time to consider where your most often used appliances and utensils are stored – are they in easy to reach locations? Utilizing pull-out shelves and lazy susans in cabinets reduces the need to reach or bend extensively which in turn improves fall risk. It's common to have rugs throughout the kitchen, consider removing or securing rugs with rug tape to reduce the likelihood of tripping.

## Home Technology

Integration of smart home devices such as smart speakers, voice-activated lights, thermostats, or security systems reduces the need for manual adjustments and can enhance daily routines. Smart

home technology can also be synonymous within fall detection systems, helping individuals and their caregivers in the event of a fall. Smart home technology can be a simple “plug and play” set up, or extensive with multiple connected speakers and pieces of technology. Common uses for smart speaker systems may be asking questions such as date and weather, video conferencing with family, or turning lights on/off.

## Home Maintenance

Last, but not least, is the importance of regular home maintenance. As we spend more time indoors, you may notice the need for simple fixes in your home. Winter is a great time to tighten handrails on stairs, replacing batteries in smoke detectors, and update lightbulbs to long lasting LED options. These small and at times mundane tasks ensure we can sustain a safe home environment.

**Incorporating these modifications promotes a more accessible and safer living space for individuals with PD. However, it's essential to assess the specific needs and abilities of the person with Parkinson's regularly to make further adjustments as required. Consulting with healthcare professionals or occupational therapists can provide personalized recommendations for home modifications tailored to individual needs. Improving your home environment not only reduces the risk of accidents but also promotes independence and a higher quality of life.**



# CURRENT RESEARCH

Please visit our website for more information



## **Music Based Walking Program**

Classes from Feb. 9 to April 2

Please contact Martha Hessler

[mjhessler@wustl.edu](mailto:mjhessler@wustl.edu) or 314-286-1478

## **How Deep Brain Stimulation Changes the Function of the Brain's Cortex**

Please contact Kaeli-Skye Spight

[DeepBrainStimulation@wustl.edu](mailto:DeepBrainStimulation@wustl.edu)

Please include in your email: Age and if you are with or without PD

## **Studies of Neuroinflammation in Parkinson's Disease**

Please contact Brooke Watkins

[NIL-PDinflammation@email.wustl.edu](mailto:NIL-PDinflammation@email.wustl.edu) or 314-747-3083

## **Protein and Imaging Biomarkers (PIB) Study**

Please contact Kayleigh Oberndorfer

[nil-pdpibstudy@email.wustl.edu](mailto:nil-pdpibstudy@email.wustl.edu) or 314-362-0420

## **Protein Aggregation and Neurotransmitter Deficits (PAND) Study**

Please contact Emma Carr

[nil-PANDstudy@email.wustl.edu](mailto:nil-PANDstudy@email.wustl.edu) or 314-362-7586

## **Precision-Mapping Study**

Please contact Emma Carr

[nilprecisionmapping@email.wustl.edu](mailto:nilprecisionmapping@email.wustl.edu) or 314-362-7586

## **Movement, Speech, and Thinking Study**

Please contact Jason Longhurst

[jason.longhurst@health.slu.edu](mailto:jason.longhurst@health.slu.edu) or 314-977-8533

## **Lower Back Pain Study**

Please contact Martha Hessler

[mjhessler@wustl.edu](mailto:mjhessler@wustl.edu) or 314-286-1478

## **Improving Diversity in Parkinson's Research and Care Study**

Contact Dominique Woodhouse

[woodhouse@wustl.edu](mailto:woodhouse@wustl.edu) or 618-401-2328

## **Parkinson Disease of Exercise Phase 3 Clinical Trial: SPARX3**

Contact Martha Hessler

[mjhessler@wustl.edu](mailto:mjhessler@wustl.edu) or 314-286-1478

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# ADVOCATING FOR YOUR LOVED ONE

The intricacies of long-term care can be overwhelming, especially if it is your first time navigating this system. When you have someone you love living in a long-term care community, advocating for your loved one becomes an important job.

## Advocating on an Individual Scale

Advocating for your loved one doesn't have to be formal all of the time. For many, the most effective and easiest way to advocate is to visit. When you visit, check on your loved one, and help them to get what they need, when they need it.

Unfortunately, not everyone can visit in person regularly. For these individuals, reaching out and advocating via phone is the best option. Sometimes, it isn't as easy as calling, reaching the right staff member, and coming up with a solution to the problem. Instead, families find barriers like difficulty getting ahold of anyone or problems working with the long-term care community. There are ways to improve your communication with long-term care communities to get better results when you advocate for your loved one.

### ► TIPS FOR COMMUNICATING WITH LONG-TERM CARE COMMUNITIES

- 1. Establish a point of contact:** The staff are providing direct patient care and aren't always able to field multiple phone calls. Work with the facility to understand who you should call with concerns. You may need to establish two contact points, one for general needs and one for nursing concerns.
- 2. Establish expectations for returned calls:** If you call your point of contact and leave a message, you might be tempted to call back and reach out to someone else. If this is not an emergency, wait for a callback, but ensure that you are waiting for a reasonable timeframe. Establish this timeframe beforehand. If the long-term care community says you can expect a callback within 24 hours, and no one returns your call in that timeframe, you can reach out to them again or ask to speak with someone higher up in the chain of command.
- 3. Take notes:** As you talk about your concerns, more issues will come up. It is easy to get sidetracked. Take notes so you have something to refer back to during phone calls, meetings, and check-ins.
- 4. Establish specific resolutions to issues:** When discussing concerns, you and the community will work together to determine a resolution. Establish a specific and tangible resolution that you can check on the progress and hold the long-term care community accountable.
- 5. Follow Up:** Once you have reached a resolution, follow up. Check-in with your loved one and the long-term care community. Find out if they have done what they said they were going to do. If not, find out why.
- 6. Contact your ombudsman:** We are here to help. If you feel like you aren't making progress, call us. If you aren't sure whether your loved one's rights are being upheld, whether you are being ignored, or whether you need additional assistance, we are here. Our confidential and free program provides you with the education and support you need to advocate for your loved one.

## Advocating for Your Loved One and Others on a Larger Scale

There may come a time that you realize that the issues you face are systemic problems. This is when advocating for your loved one can look even bigger. Now more than ever, families want to help. They want to know what they can do to advocate, not just for their loved ones but for all residents in long-term care. Fortunately, there are things you can do to help this vulnerable population.

### ► WAYS TO HELP

- 1. Tell your story:** When residents and their loved ones agree to share their stories, we are better prepared to advocate for real systemic change.
- 2. Find resources:** Consumer Voice also has resources for families, including ideas to stay connected and ways that families can advocate.
- 3. Watch webinars:** VOYCE hosts monthly webinars that you can watch live or later in our Library. Check out our upcoming Community Education sessions.
- 4. Look into organizations that are advocating:** Consumer Voice, Center for Medicare Advocacy, Long-Term Care Community Coalition, and Justice in Aging are some of the organizations advocating for long-term care residents on a national scale.
- 5. Reach out to your representative:** Discuss your concerns with your representative and let them know what their constituents would like to see for residents.
- 6. Receive updates:** VOYCE has a policy and advocacy program dedicated to engaging in individual and systematic advocacy. You can sign up to receive advocacy updates.

*Families and concerned individuals want to help their loved ones in long-term care. Your dedication and passion improve your loved one's quality of life in long-term care.*

Shared from [www.voycestl.org](http://www.voycestl.org)

*If you would like to speak to a Home Care Ombudsman, you can call the Department on Aging Senior Helpline*

#### MISSOURI

St. Louis - Voyce 314-919-8222  
Missouri – 800-309-3282  
[LTCOmbudsman@health.mo.gov](mailto:LTCOmbudsman@health.mo.gov)

#### ILLINOIS

Call: 1-800-252-8966  
or email [Aging.HCOProgram@illinois.gov](mailto:Aging.HCOProgram@illinois.gov)  
<https://ilaging.illinois.gov/programs/ltcombudsman>



# EXERCISE CLASS SCHEDULE

For more information please refer to [www.apdaparkinson.org/mo](http://www.apdaparkinson.org/mo) or call 636.778.3377

## MISSOURI CLASS SCHEDULE

### Chesterfield APDA Office

Tuesday 10:00am - Circuit Training | Level 3  
Tuesday 11:00am - Strength and Cardio | Level 2  
Tuesday 12:00pm - Dancing through the Decades  
Wednesday 10:00am - Movement Training | Level 2  
Wednesday 11:00am - Seated Exercise | Level 1  
Thursday 11:00am - Tai Chi for Parkinson's  
Thursday 12:00pm - Parkinson's Boxing | Level 3  
Thursday 1:00pm - Strength and Cardio | Level 2  
Friday 11:00am - Tai Chi and Meditation

### Chesterfield YMCA

Mon/Wed 12:15pm - Parkinson's Pedalers | Level 2

*\*NEW Class Starting March 5th*

### Crestwood - Sports Medicine & Training Ctr.

Tuesday 9:00am - Exercise for Parkinson's | Level 2

### Eureka - The Timbers Recreation Center

Tues/Thurs 1:00pm - Exercise for Parkinson's

### Jefferson County YMCA

Mon/Thurs 10:00am - Exercise for Parkinson's

### Kirkwood YMCA

Monday 11:45am - Parkinson's Pedalers | Levels 2

### Maryland Heights YMCA

Tuesday 11:00am - Exercise for Parkinson's | Level 2

### South County YMCA

Monday 9:30am - Exercise for Parkinson's  
Thursday 9:30am - Exercise for Parkinson's

### St. Louis City - Stephen A. Orthwein Center

Thursday 12:00pm - Interval Training | Level 2

### St. Peters - BJC

Thursday 10:00am - Strength and Cardio | Level 2  
Thursday 11:00am - Seated Exercise | Level 1

### Ste. Genevieve Co. Community Center

Wednesday 11:00am - Exercise for Parkinson's | Level 2

### Sunset Hills - Friendship Village

Thursday 1:00pm - Movement Training | Level 2  
*(NOTE: Schedule varies, please call ahead to confirm)*

*\*NEW Class Starting March 5th*

### Warrenton - SSM Day Institute

1st & 3rd Tuesdays 3:30pm - Exercise for Parkinson's

### Washington YMCA

Mon/Wed 1:00pm - Exercise for Parkinson's  
Friday 11:30am - Exercise for Parkinson's

### Virtual via Zoom

Tues 9:00am, Thurs 2:00pm - Seated Exercise | Level 1

## ILLINOIS CLASS SCHEDULE

### Breese/Clinton Co. YMCA

Tues/Thurs 12:30pm - Exercise for Parkinson's

### Carlinville Area Hospital

Tuesday 10:00am - Exercise for Parkinson's

### Champaign YMCA

Monday 1:00pm - Strength and Balance  
Tuesday 1:00pm - Functional Chair Fitness  
Wednesday 1:00pm - Seated Yoga  
Thursday 1:00pm - Parkinson's Fitness  
Friday 1:00pm - Functional Chair Fitness

### Decatur YMCA

Mon/Wed/Fri 11:00am - Parkinson's Pedalers  
Tues/Thurs 9:00am - Parkinson's on the Move

### Edwardsville YMCA

Tues/Thurs 11:00am - Exercise for Parkinson's

### Highland - Korte Recreation Center

Mon/Wed/Thurs 11:00am - Cycle and Strength

### O'Fallon YMCA

Tues/Thurs 12:00pm - Exercise for Parkinson's

### Quincy YMCA

Tues/Fri 10:30am - Fit to Fight PD Boxing

### Springfield - Grant Conservatory of Music & Dance

*\*New Location*

Tues/Thurs 1:30pm - The Joy of Movement

### Virtual via Zoom

Wednesday 10:30am - The Joy of Movement

### Exercise Level Descriptions:

Level 1: Participants exercise seated or standing with support. Movements are done at a pace and intensity that are appropriate for each participant.

Level 2: Participants must be able to walk and stand up from a chair without assistance. Most exercises are done standing.

Level 3: Higher intensity, faster paced classes where participants perform multiple step exercises and may get on/off the floor.

# SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email [apdamo@apdaparkinson.org](mailto:apdamo@apdaparkinson.org)

## MISSOURI SUPPORT GROUPS

**Ballwin - Meramec Bluffs Care Center**  
4th Tuesday 2:30pm

**Cape Girardeau - Cape Girardeau Library**  
2nd Monday 5:30pm

**Chesterfield - APDA Office**  
2nd Monday 10:30am - Caregivers ONLY  
2nd Tuesday 1:00pm - Newly Diagnosed (at capacity)  
3rd Friday 2:00pm - We Care: South Asian families  
**\*Coming In April** | 4th Tuesday 1:00pm - Newly Diagnosed

**Chesterfield - Friendship Village, Trillium Rm.**  
3rd Thursday 2:00pm

**Florissant - Garden Villas North**  
1st Tuesday 10:00am

**Kansas City - Johnson County Rehab Hospital**  
2nd Wednesday 4:00pm

**Kirkwood - First Presbyterian Church**  
2nd Monday 1:30pm

**\*NEW | Kirkwood - SPEAKeasy Therapies & Fitness**  
2nd Wednesday 6:00pm - Young onset ONLY

**Olivette - Private Home Care Co - Hybrid**  
3rd Tuesday 11:00am

**Rolla - Phelps Health Cancer Institute, Conf. Rm. B**  
3rd Tuesday 2:30pm

**South County - Cedarhurst of Tesson Heights**  
4th Wednesday 10:00am

**\*NEW | St. Charles - Kisker Road Library**  
2nd Tuesday 10:00am - Caregivers ONLY

**Ste. Genevieve - Community Center**  
2nd Wednesday 10:00am

**St. Peters - Breeze Park Independent Living**  
1st Tuesday 1:00pm

**Washington - Public Library**  
2nd Monday 3:00pm

**Virtual via Zoom**  
4th Tuesday 6:30pm - All welcome  
3rd Monday 1:00pm - Caregivers ONLY  
Every Thursday 6:00pm - Young onset ONLY

## ILLINOIS SUPPORT GROUPS

**Alton - SSP Main Bldg., The Meeting Room**  
2nd Wednesday 1:00pm

**Alton - SSP Wellness Center**  
2nd Tuesday 2:00pm - Caregivers ONLY

**Belleville - Southwestern Illinois College's  
Programs and Services for Older Persons**  
3rd Monday 1:30pm

**Carbondale - Prairie Living at Chautauqua**  
1st Wednesday 1:00pm

**Carlinville - Carlinville Area Hospital,  
MOB Comm Rm.**  
4th Tuesday 11:00am

**Champaign - Savoy United Methodist Church**  
Every Monday 10:00am

**Decatur - Westminister Presbyterian Church**  
3rd Thursday 1:30pm

**Edwardsville - YMCA Niebur Center**  
1st Tuesday 2:00pm

**Greenville - Bond County Senior Citizens**  
2nd Tuesday 1:00pm

**Highland - St. Joseph Hospital, Sullivan Conf. Rm.**  
4th Tuesday 2:00pm

**Quincy  
Public Library** | 2nd Saturday 10:00am  
**Senior Center** | 4th Thursday 1:00pm - (small group)

**Virtual via Zoom - Jacksonville**  
1st Wednesday 1:00pm

# COGNITIVE DECLINE IN PARKINSON'S DISEASE - IS THERE ANYTHING WE CAN DO ABOUT IT?

*Dr. Gilbert's blog post for March 5, 2019*

For many people, one of the most concerning non-motor features of Parkinson's disease (PD) is cognitive decline. Attention, working memory, executive function, memory, language and visual reasoning are the cognitive skills most frequently affected in PD.

Cognitive changes can be an underlying part of PD, caused by abnormal accumulation of the protein alpha-synuclein into Lewy bodies in the thinking areas of the brain. When this occurs, there are strategies ranging from cognitive therapy to medications to help support cognitive function.

On the vast array of treatable medical problems that can worsen cognitive function. The following factors are crucial to identify, because if they are treated, cognitive function may improve.

## Hearing Loss & Cognitive Decline

Abundant research exists that supports the claim that hearing loss impacts cognitive function. One Johns Hopkins research study reviewed thousands of medical claims and demonstrated an association between hearing loss and an increased 10-year risk of dementia, falls, depression and heart attack. Research also suggests that improving hearing with hearing aids can improve cognitive function. One study showed that memory decline slowed in patients who started wearing hearing aids, highlighting the importance of detecting and treating hearing loss early.

## Other Possible Contributors to Cognitive Decline in Parkinson's

Hearing is not the only modifiable contributor to cognitive decline. Consider reviewing this list with your doctor to make sure that you do not need to be evaluated for any of these conditions:

- **Medication effects**

Certain medications given for urinary frequency, migraine, seizures, anxiety, and other conditions, can interfere with cognitive function or make your thinking feel sluggish. Even some medications given for PD can contribute to this problem, so be sure to review your medication list frequently with your neurologist and speak up if you're noticing changes in your cognitive abilities. If a medication is identified that can worsen cognitive function, it can be changed.

- **Intercurrent infection**

If cognitive difficulty (or hallucinations) seem to start or worsen quickly, it is important to check for a urinary tract infection or pneumonia. If an infection is identified, it can be treated with antibiotics.

- **Depression**

It is well established that depression can mimic cognitive decline. When someone is depressed, he/she tends to withdraw socially and not exert themselves cognitively. When this occurs, the condition is referred to as pseudo-dementia, and with proper treatment of the depression, cognitive function can be restored.

- **Abnormal thyroid function**

Cognitive difficulties can result from too little thyroid hormone which can be easily checked with a blood test and corrected with a prescription of synthetic thyroid hormone.

- **Abnormal Vitamin B12 levels**

Cognitive difficulties can also result from low levels of Vitamin B12. This can also be easily checked with a blood test and corrected by taking supplemental Vitamin B12.





- **Orthostatic hypotension**

Periodic drops in blood pressure may occur as a non-motor symptom in PD. During periods of low blood pressure, cognitive function may decline because of decreased blood flow to the thinking parts of the brain.

- **Dehydration**

Dehydration can exacerbate low blood pressure and can contribute to changes in alertness.

- **Vascular brain health**

Poor circulation of blood to the brain, often due to narrowed or damaged arteries from high blood pressure, high cholesterol and diabetes, can cause strokes. Strokes can be apparent and result in a sudden neurologic deficit such as the inability to move one side, or to speak. Strokes can also be silent and not cause any noticeable neurologic deficit, if they affect areas of the brain that are not involved in particular functions. However, an accumulation of both these types of strokes can contribute to cognitive decline.

- **Poor sleep and sleep apnea**

Poor sleep from Parkinson's disease typically leads to daytime fatigue which can make cognitive tasks more difficult. Sleep apnea, which often is suspected due to persistent, loud snoring, is one cause of poor sleep which has an increased incidence in people with PD. In the general population, this condition is often associated with obesity, with fat deposits in the upper airway resulting in obstruction of normal breathing at night. In PD however, the condition may

be due to a combination of factors including rigidity, hypokinesia and postural abnormalities of the trunk muscles as well as autonomic dysfunction. Another contributor to the disordered breathing of PD may be abnormal signaling from sleep and respiratory centers in the brain. Regardless of the cause, in this condition, there are frequent awakenings during the night, due to intermittent starts and stops of breathing and resultant episodes of drops in blood oxygen levels. If sleep apnea is detected, it can be treated with an array of breathing devices which can supports breathing at night.

- **Head trauma**

As you may be aware, past head trauma likely contributes to a small increased risk of PD. When cognitive changes occur, they may be related to a more acute head trauma. A fall which results in hitting the head, for example, may cause bleeding in various areas in and around the brain. Usually, it will be clear that a trip to the emergency room is necessary because of changes in consciousness. Sometimes, however, the injury may seem mild even though it caused internal bleeding. For example, bleeding in the subdural space around the brain could be slow and subtle and result in cognitive changes that develop over weeks to months. Therefore, it is generally recommended that after even minor head injury if there is headache, vomiting, short-term memory loss, seizure or visible trauma above the collar bone, a computed tomography (CT) of the head is performed.

# TRIBUTES AND DONATIONS 10.01.2023 thru 12.31.2023

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## APDA Missouri Chapter

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