



# AMERICAN PARKINSON DISEASE ASSOCIATION

## MISSOURI CHAPTER NEWSLETTER

Jan/Feb/March  
2025  
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## THOUGHTS ON BRAIN DONATIONS

*By Joel S. Permuter, MD*

Elliot Stein Family Professor of Neurology, Section Head, Movement Disorders, Professor of Radiology, Neuroscience, Physical Therapy, and Occupational Therapy Washington University School of Medicine St. Louis, MO



The Movement Disorder Brain Bank is an extremely valuable research asset. Several discoveries have been made regarding the causes of some of the manifestations of Parkinson disease and identified potential new targets for treatment. Some of the findings have been particularly surprising and required direct brain examinations. None of this work is possible without the generous help of those who donate their brain for our research studies. Many patients and their families want to help. This article will explain how this can be done.

These brain studies require substantial work and resources. The scarcest resource is available brain tissue; so we want to optimally learn from these studies. We clearly learn the most from these brain studies by comparing our findings to what we have learned about each individual's manifestations of PD. The most is learned from those who participate in our long-term research studies that includes brain donation. Participation in a study means we collect other data that we can use in conjunction with the autopsy results, and we learn much more. Participants in these studies have provided permission for brain donation and have discussed this with their families to ensure a smooth procedure at a difficult time.

To facilitate donation whether in a study or not, it is extremely helpful for a patient and family to provide written consent for the procedure before death. There is often a consent form to fill out to enable a smooth process. It is also important for the family to be aware of the patient's wishes to donate and make sure to call our exchange (314-388-6138) at the time of death. We provide patients a stylish bracelet that includes notification of brain donor status and who to call at the time of passing.

Having the brain donation consent form on file with us facilitates the donation, but verbal consent also can be obtained over the phone. If this occurs at night or on the weekends, the family should call the exchange and ask for the patient's Movement Disorder doctor. Please note, that we can only do this for people that have been followed in the Movement Disorders Center.

Please note that brain donation does not interfere with any planned funeral arrangements. If a patient's family is planning an open casket funeral there will be

# THOUGHTS ON BRAIN DONATIONS (continued)

no sign of the brain donation. We work with the family to complete the retrieval as quickly as possible to not disrupt any funeral plans. A report can take up to 4 years. You can request the physician to call and discuss it when finalized.

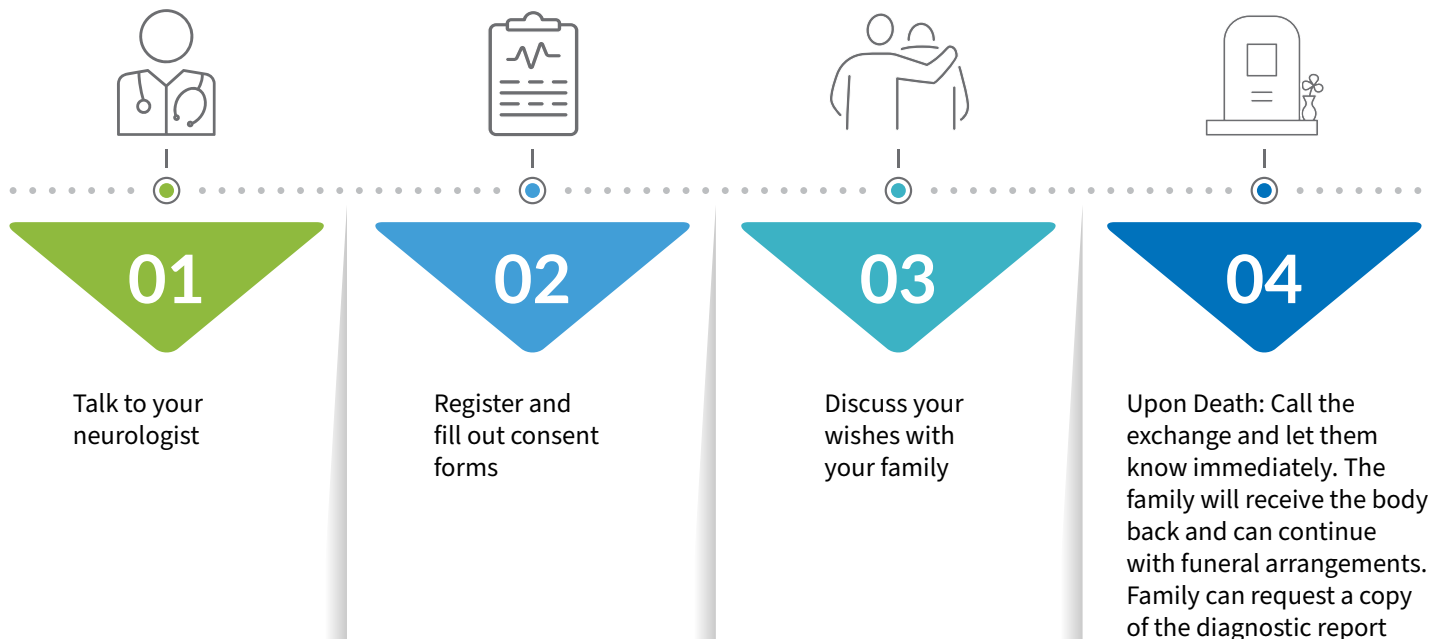
Finally, brain donation is an amazing gift that moves forward our understanding of Parkinson disease. There is no greater gift. Together, we can continue the fight against Parkinson disease.

Now that you know how to sign up for brain donation, let me review some of the amazing new information that we have found in our studies. Several studies have investigated the role of abnormal alpha-synuclein has in thinking problems that occur in many people with PD. Recall that alpha-synuclein is a protein in the brain that forms clumps that are called Lewy bodies. These occur in areas of the brain with dying nerve cells.

When abnormal alpha-synuclein affects nerves in the brainstem, the lower part of the brain, it relates to movement problems that occur in PD. Involvement of

higher parts of the brain can lead to thinking problems. Initially it was thought that a combination of Lewy bodies and other abnormal proteins that are associated with Alzheimer disease caused this in people with PD. We have found that mostly the alpha-synuclein Lewy bodies relate to thinking problems. We found that 35% of people with PD who did not have dementia still had severe abnormal synuclein in these higher brain areas. Thus, alpha-synuclein in higher brain regions is neither necessary nor sufficient to cause dementia in people with PD. Another study suggests that loss of other brain chemical messengers could be culprit. These other chemical messengers called serotonin and norepinephrine are nearly completely lost in higher brain regions – which could potentially be new targets for treatment.

Brain donations have made these discoveries possible. Multiple other studies are underway. All of these are only possible with brain donations from people with PD and those that do not have PD. This research is clearly a partnership between clinician scientists and the community.



More information at [brainsupportnetwork.org](http://brainsupportnetwork.org) and [braindonorproject.org](http://braindonorproject.org).

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**Tips and Tricks for Parkinson's**

**Driving**



Plan your trips: Choose familiar routes, beat rush hour, stay home in bad weather, and prioritize driving in the daylight if vision is affected.



Easy Entry and Exit: Utilize a swivel seat cushion, leg lifter and/or car cane to assist with getting in and out of the car. Add a thicker steering wheel cover with grips for a more secure grasp



Passenger Support: Have a friend or family accompany you while you drive long distances



Sitting down while getting ready to go out will conserve energy and support balance.



# GETTING TAX BENEFITS WHILE DONATING TO YOUR FAVORITE ORGANIZATION



By Anne Haudrich, CFP® - Senior Advisor at Moneta



Happy New Years! Have you ever considered there may be a more tax-efficient way to donate to the APDA other than paying with a credit card or sending in a check? Donating cash from your bank account makes you eligible for the charitable deduction on your tax return (assuming you itemize your deductions), but did you know depending on your age and financial situation, there may be other options to consider? If you're looking to make a significant impact to the APDA with your gift, consider donating appreciated securities or utilizing a Qualified Charitable Distribution (QCD).

A Qualified Charitable Distribution is a donation to a 501(c)(3) charitable organization made directly from your Traditional Individual Retirement Account (IRA) – it cannot be paid to you first. If you are at least 70.5 years old, you can direct any amount up to \$110,000 to a charitable organization from your IRA without paying taxes on the distribution. Because your charitable contribution is a tax-free distribution from your IRA, you do not take the charitable deduction on your tax return. This technique is especially effective for those who are subject to a Required Minimum Distribution (RMD) and for those who typically elect the standard deduction on their federal tax return. Please consult your tax and/or financial advisor to see if this technique would be beneficial, and remember, you cannot make a QCD from employer-sponsored IRAs, like SIMPLEs or SEPs.

If you are not eligible for a QCD, donating appreciated securities from a taxable account (non-retirement, like a brokerage account) may be another option for you. Appreciated securities (Exchange Traded Funds (ETFs), stocks, or mutual funds, to name a few) that have increased in value which you have held for longer than one year can be donated to the APDA “in-kind.”

The benefit of using shares of appreciated securities is that you can transfer the unrealized gain out of your account and over to the APDA where they are able to sell and are not subject to the capital gains tax. This is especially effective if you are someone who typically sells some of your investments to fulfill your charitable intentions – consider instead donating the shares rather than selling to potentially avoid a realized capital gain that may be taxable. Again, consult your tax advisor as to whether this technique will be beneficial to you, as there are some other factors to consider like how much of your gift can be deducted based on your Adjusted Gross Income (AGI).

While for most, charitable giving isn't just about the tax benefit, if you intend to support the APDA and can do so in a more tax-efficient manner, I see that as a win-win. Wishing everyone a wonderful holiday season surrounded by your loved ones.

## *Disclosures:*

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# WELCOME NEW EXECUTIVE DIRECTOR Beth Elders



“Beth’s experience and accomplishments in the non-profit and private sectors will be an asset to APDA,” states Leslie A. Chambers, President & CEO, APDA. “Her demonstrated leadership will enhance our mission delivery, generate critical funds, maximize our community-based Programs and services, and ultimately increase our ability to serve more people with PD. “

Elders joins APDA with more than 15 years of non-profit leadership experience at organizations including the American Red Cross of Greater St. Louis, most recently serving there as Executive Director. She has a proven background in fundraising, cross-functional team empowerment, and data-driven decision making, and holds master’s degrees from the University of Missouri and Northwestern University and certifications in non-profit project management from Washington University.

**apda** AMERICAN  
PARKINSON DISEASE  
ASSOCIATION

MISSOURI CHAPTER

Strength in optimism. Hope in progress.

## 2025 APDA MIDWEST PARKINSON’S CONFERENCE



Scan for more information  
and to register

*Save the  
date*

**Thursday, May 1 12:30 - 4:00pm**  
(doors open at 11:30am)

**Manchester United Methodist Church**

129 Woods Mill Road  
Manchester, MO 63011

*Check out the New Location*

# 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

### Carondelet YMCA

Tuesday 11:00am - Parkinson's Pedalers  
Friday 12:00pm - Exercise for Parkinson's

### Chesterfield APDA Office

Tuesday 9:00am - Seated Exercise | Level 1  
Tuesday 10:00am - Circuit Training | Level 3  
Tuesday 11:00am - Strength and Cardio | Level 2  
Tuesday 12:00pm - Music & Movement for PD | Level 2  
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  
Thursday 2:00pm - Seated Exercise | Level 1  
Friday 11:00am - Tai Chi and Meditation

### Chesterfield YMCA

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

### Crestwood - Sports Medicine & Training Ctr.

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

### Eureka - The Timbers Recreation Center

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

### Jefferson County YMCA

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

### Kirkwood YMCA

Monday 11:45am - Parkinson's Pedalers

### Maryland Heights YMCA

Tues/Thurs 11:30am - Exercise for Parkinson's | Level 2

### South County YMCA

Tues/Thurs 3:00pm - Exercise for Parkinson's

### *\*NEW* | St. Charles - SSM Day Institute

1st & 3rd Tues 3:30pm - Exercise for Parkinson's | Levels 1 & 2

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

Thursday 12:00pm - Interval Training | Level 2

### St. Peters - BJC - Medical Office Building 1

*(Note: These classes are full at this time)*

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 1:30pm *(Note: New Time)*

### Warrenton - SSM Day Institute

1st and 3rd Tues 3:30pm - Exercise for Parkinson's | Levels 1 and 2

### Washington YMCA

Mon/Wed 1:00pm - Exercise for Parkinson's

Friday 11:30am - Exercise for Parkinson's

### Virtual via Zoom

Tuesday 9:00am - Seated Exercise | Level 1

Thursday 2:00pm - Seated Exercise | Level 1

## ILLINOIS CLASS SCHEDULE

### Downtown Belleville YMCA

Mon/Wed 11:00am - Exercise for Parkinson's

### East Belleville YMCA

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

### Breese/Clinton Co. YMCA

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

### Carlinville Area Hospital

Tuesday 10:00am - Exercise for Parkinson's

### 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 - Parkinson's Pedalers

### O'Fallon YMCA

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

### Quincy YMCA

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

### Springfield - First Christian Church

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 2:00pm

### **Cape Girardeau - Cape Girardeau Library**

2nd Monday 5:30pm

### **Chesterfield - APDA Office**

2nd Monday 10:30am - Caregivers ONLY  
2nd Tuesday 1:00pm - Early in diagnoses  
4th Tuesday 1:00pm - Newly diagnosed

### **Florissant - Garden Villas North**

1st Tuesday 10:00am

### **Kansas City - Johnson County Rehab Hospital**

2nd Wednesday 4:00pm

### **Olivette - Private Home Care Company - 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 | South City (St. Louis) -**

#### **Carondelet Park Rec Plex**

2nd Tuesday 12:10pm

#### **St. Charles - Kisker Road Library**

2nd Tuesday 10:00am - Caregivers ONLY

#### **Ste. Genevieve - Community Center**

2nd Wednesday 10:00am

#### **St. Peters - Spencer Road Library**

1st Tuesday 1:00pm

#### **Sullivan - *COMING SOON!***

#### **Washington - Public Library**

2nd Monday 3:00pm

#### **Virtual via Zoom - Register online for link**

3rd Monday 1:00pm - Caregivers ONLY  
4th Tuesday 6:30pm - All welcome  
2nd Wednesday 9:00am - Adult Children ONLY  
Every Thursday 6:00pm - Young onset ONLY  
2nd Thursday 10:00am - African American families  
3rd Friday 2:00pm - We Care: South Asian families

## ILLINOIS SUPPORT GROUPS

### **Alton - SSP Wellness Center**

2nd Tuesday 2:00pm - Caregivers ONLY  
2nd Wednesday 2:00pm

### **Belleville - Southwestern Illinois College's Programs & 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

### **\*NEW | Centralia - Heritage Woods of Centralia**

2nd Wednesday 2:00pm

### **Edwardsville - YMCA Niebur Center**

1st Tuesday 2:00pm

### **Greenville - Bond County Senior Citizens**

2nd Tuesday 1:00pm

### **Highland - St. Joseph Hospital, Sullivan Conf. Rm.**

2nd Wednesday 2:00pm

### **Quincy**

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

# IMPROVING YOUR COGNITIVE FITNESS: MORE THAN PUZZLES



*By Cassandra Serrata,  
MS CCC-SLP, Speech  
Language Pathologist  
and owner of  
Connect Therapy*

It's estimated that 20-50% of people with PD experience mild cognitive impairment (MCI). MCI can include problems with memory, language and problem solving. MCI is the stage between typical age-related cognitive changes and the more severe cognitive decline of dementia. As people age, it's common to be forgetful and occasionally lose the keys or forget a person's name or a word. But this does not impact a person's ability to function and perform daily activities. A person with MCI will demonstrate cognitive changes that do impact daily functioning and tasks, such as missing appointments or social events, losing your place in a conversation or forgetting the names of friends and family. Symptoms of MCI can stay the same or worsen over time.

Cognition refers to all forms of knowing and awareness, meaning our ability to process information and apply it. **The areas of cognition include:**

- **Attention**
- **Language**
- **Memory**
- **Executive functions**
- **Visuospatial skills**

Cognitive changes in PD happen because of protein accumulation in regions of the brain that are responsible for these cognitive processes. Cognitive changes in PD can range from mild to severe and can change over time as PD progresses. PD isn't the only thing that impacts cognition and it's important to know other factors that can contribute to cognitive impairment. Medical illnesses, seizures, strokes, traumatic brain injury and mental health disorders can impair cognitive functions.

If you or a loved one is experiencing mild cognitive decline (MCI), seeking medical advice is recommended. Diagnosing MCI can be done by a primary care provider, neurologist, occupational therapist or speech language pathologist. Once diagnosed, intervention can be helpful to maintain independence and train cognitive strategies. An occupational therapist can assist with complex activities of daily living, such as medication management, cooking, driving, etc. A speech language pathologist assists with cognitive communication, including word finding, memory strategies, executive functions and attention.

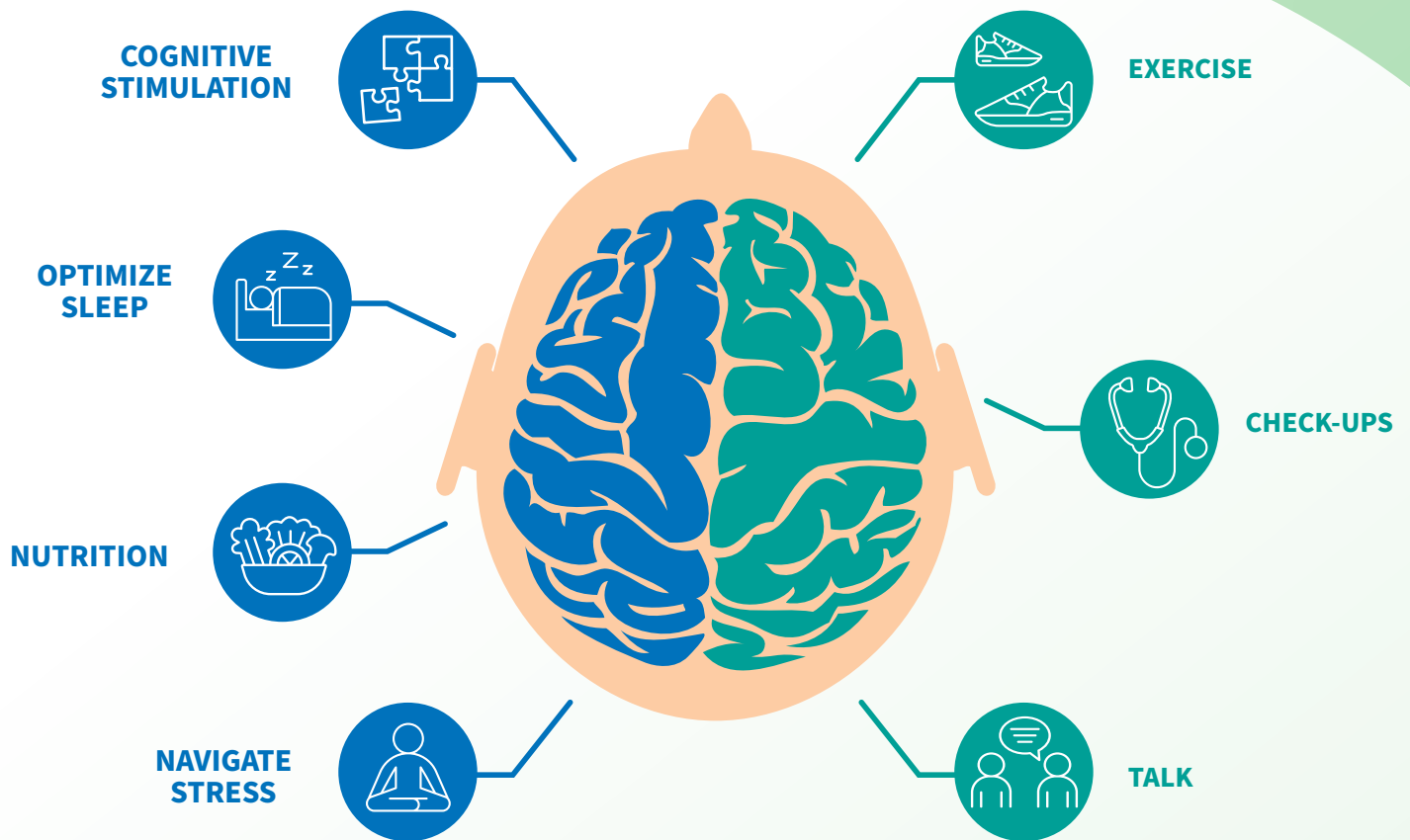
In recent years, there has been more research done in our brain's ability to build new neural networks and improve, or at least maintain, cognitive abilities as we age. Researchers have determined a set of principles that help to optimize brain health and function and have coined the term Cognitive Fitness.

Cognitive Fitness is a state of optimized ability to learn, remember, reason, plan and adapt. The more cognitively fit you are, the better you are at making decisions, solving problems and dealing with stress and change. Cognitive fitness can be helpful for all of us, not just those who are experience MCI. Focusing on brain and cognitive health helps to improve independence and quality of life.

**Here are the key principles to maintain an engaged brain:**

**Cognitive Stimulation:** Complete any form of mental stimulation that you enjoy on a daily basis. If you enjoy jigsaw puzzles and crosswords, keep doing them! But if you're looking for more ideas, here are some other cognitive exercises you might like to try: learn something new (new language, new boardgame, new hobby), card games, word games, listen to a podcast, read an article or book, sudoku and more. Any activity that makes you think is a mental exercise.





**Optimize Sleep:** Maintain a healthy sleep routine for brain health. Adults should aim to get 7-9 hours of sleep per night. Create routines that optimize sleep, such as avoiding screens before bed and stick to a routine where you wake up and go to bed at the same time every day. Good sleep improves your physical and mental health. Sleep disturbances are common in PD. Talk with your doctor about medications and sleep treatments.

**Nutrition:** Your diet impacts your brain health. Aim for a diet containing abundant fruits, vegetables, legumes, nuts and whole grains. Limit the amount of animal products, instead opt for plant-based protein such as beans, nuts, chia seeds, legumes and quinoa.

**Navigate Stress:** Finding healthy ways to manage stress is important for your cognitive health. Ideas of stress management include: deep breathing, going for a walk, meditation, calling a friend or relative, yoga and therapy.

**Exercise:** Physical activity strengthens brain health. Adults with PD should aim for 150 minutes of exercise per week. This includes aerobic activity, strength training, balance and flexibility. Find the type of exercise you enjoy, so you'll stick with it.

**Check-ups:** Managing your medical health is a vital part of brain health. Staying up to date with all medical providers, managing chronic disease and taking your medications as prescribed are important ways to help take care of your brain.

**Talk:** Socialization improves brain health by stimulating the brain and challenging your thinking. Social interactions can lead to new neural connections and helps to boost mood. Consider combining a few principles and taking an exercise class which can help with exercise, socialization and cognitive stimulation all at once!

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09.01.2024 thru 11.30.2024

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