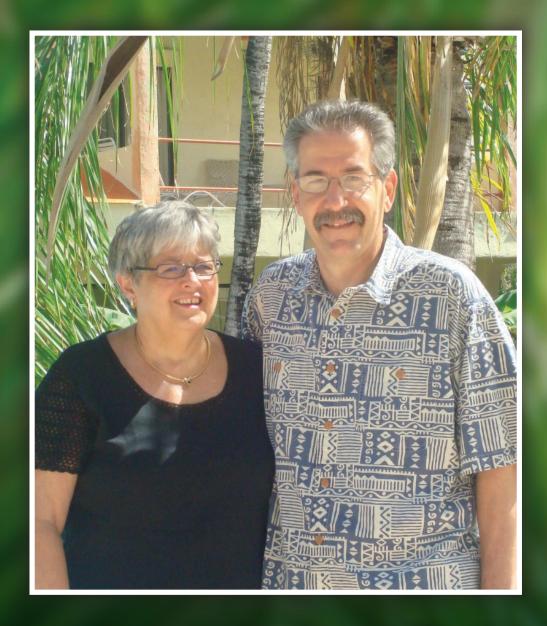


A Resource for Iowans with Parkinson's Disease and those who care for them.



"Using MAPS to Find Her Way"

An Interview with Lynhon Stout by Anne Scherer



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Reader Submissions

Live it! magazine is intended to be a voice for the Parkinson's disease community. We encourage and are pleased to consider your words, an article, art, and photo submissions for future issues from our readers - anything that shows how you Live It! Please send your submission requests to Iowa Parkinson's Disease Association, PO Box 643, Ankeny, IA 50021 with Live It! On the attention line, or email them to apdaiowa@parkinson.org. Please note: The decision to include reader submissions is at the discretion of the editorial staff. The editorial staff reserves the right to edit or otherwise alter any material submitted. If you would like submission material returned to you, please include a stamped, self-addressed envelope.

Disclaimer

All material related to Parkinson's disease contained in this magazine is solely for the information of the reader. It should not be used for treatment purposes, but rather for discussion with the patient's physician. Specific articles reflect the opinion of the writer and are not necessarily the opinion of the editorial staff, the medical director, The Iowa Chapter of APDA, or the APDA.

from the Board President



Jeff Raines President, American Parkinson's Disease Association, Iowa Chapter

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Making Life with PD a Better Place

Thank you to our many amazing volunteers from our staff- Susan Callison, Program Coordinator and Natasha Winterbottom, Fundraising and Event Manager "We couldn't do it without you!"

With volunteers like ours at APDA lowa, we have a chance to make life with PD a better place. We are so grateful for all your hard work. It makes all the difference in our world!

Here's just a few of our volunteer groups

- Conference 2023 Volunteers
- PD Moves Volunteers from the community and DMU Students
- · APDA committee volunteers
- · Event Planning committees
- C4 Workout Volunteers
- · Golf Putting for Parkinson's
- · Shake Rattle and Stroll
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- Eastern Iowa Conference

With our volunteers, any impossible task becomes accomplishable. Thank you for furthering the cause. You are truly a gift.

As we plan for our future more volunteers are needed!

If you would like to join our volunteer team, contact

- Susan at scallison@apdaparkinson.org or (515) 782-4386 or
- Natasha at nwinterbottom@apdaparkinson.org or (515) 782-3833.
- Or visit our website at www.apdaparkinson.org/community/iowa

Be blessed my friends,

Jeff Raines



from our medical director

The lowa Parkinson Disease Association, lowa Chapter, and Live It! Magazine are privileged to have board-certified clinical neurologist Lynn K. Struck MD as our advisory medical director. Dr. Struck is on staff with Unity Point Health Physicians, Des Moines, and is a leading expert in movement disorders in lowa. She has focused her career on advances in treatment of her many patients with Parkinson's disease and ongoing research to find better treatments and, ultimately, a cure.



Lynn K. Struck, MDNeurologist
Physician Specialty Clinic
UnityPoint Health – Des Moines

Parkinson Disease Epidemiology

The recent June 16 Parkinson conference had so much valuable information. If you attended, you can review conference videos on the APDA lowa website (www.apdaparkiinson/iowa). If you were unable to attend, this is a great opportunity to learn more about your disease. Multiple topics were covered: exercise, medications, nonmotor symptoms, how to navigate PD in the hospital, etc. We also have our PD Optimism Walk this fall (Sept 30) and hope you will be able to attend. Thanks again to all our great volunteers.

Lynn K. Struck, MD

Now Online: recorded sessions and slides https://bit.ly/IAPDCon2023

Scroll down to find the recordings under Archived Conferences.

TOPIC	PRESENTER	
Get Out and Go	Linda K Olson, MD, Triple Amputee, Person with Parkinson's	
New Horizons in PD Research	Dr. Aasef Shaikh	
Motor and NonMotor Symptoms and Treatments	Dr. Alex Eischeid	
Staying Motivated on Your Fitness Journey	Javier Tuel, Tuelshed Fitness	
Building Your Health Care Team	Gail McGaughy and Tammy Miller, On With Life	
PD Strategies to Live Well	Valerie Stickel-Diehl, RN	
Deep Brain Stimulation - Is it right for me?	Dr. Jeremy Greenlee	
Managing Disability Rights in the Workplace	Cynthia Letsch, J.D. Letch Law	
SLIDES ONLY		

SLIDES ONLY Mental Health and Advancing Parkinson's Disease Medicare: making the most of your benefits Focused Ultrasound for Parkinson's Disease SLIDES ONLY Dianne Alber, PHD. Ann Goodman, SHIIP Counselor Dr. Travis Tierney

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OWA CHAPTER

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Iowa Optimism Walk

Sat, September 30, 2023

Check-in and pre-event activities: 12 Noon
Ceremony is at 1:00 pm - Walk to follow

Principal Park (Iowa Cubs)

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Walk with us and help put an end to

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What is an Optimism Walk?

- · A family-friendly short non-competitive walk
- Every six minutes someone is diagnosed with Parkinson's disease.
- The more funds we raise, the more people we can help!

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Medications

Medications Used to Treat Parkinson Disease

Kristin S. Meyer, PharmD, BCGP, CACP, FASCP

Introduction

Parkinson disease (PD) is a chronic and progressive neurological disorder that affects millions of people worldwide. It is characterized by a shortage of dopamine in the brain. This deficiency results in a wide range of motor and non-motor symptoms, such as tremors, rigidity or stiffness, bradykinesia (slowness of movement), and postural instability which can increase risk of falls. While there is currently no cure for Parkinson disease, several medications have proven effective in managing its symptoms and improving the quality of life for patients. This article will review the various classes of drugs used to treat Parkinson disease, their mechanisms of action, benefits, side effects, and the importance of personalized treatment plans.

Levodopa (L-Dopa)

Levodopa, also known as L-Dopa, is the most effective and commonly prescribed medication for Parkinson disease. It is a precursor of dopamine and can cross the blood-brain barrier, where it is converted to dopamine by dopa decarboxylase. Levodopa helps replenish dopamine levels in the brain, reducing motor symptoms and improving motor function. It is commonly combined with carbidopa, which helps deliver more active levodopa to the brain.

Levodopa Products: Dhivy®, Duopa®, Inbrija®, Parcopa®, Rytary®, Sinemet®, Stalevo®

Benefits: Levodopa provides significant relief from motor symptoms, such as bradykinesia and rigidity, leading to improved mobility and overall quality of life. It remains the gold standard for managing PD symptoms. There are several products to choose from and the dose can be highly individualized.

Common Side Effects: The most common side effects of levodopa are nausea, orthostatic hypotension, and hallucinations. Tolerance can develop to these side effects over time and dose adjustment can help. Long-term use of levodopa can lead to motor fluctuations and dyskinesias (involuntary movements).

Special Note: Foods high in protein (meat, eggs, dairy) can sometimes interfere with the absorption of levodopa. This affects every person differently and can be addressed by separating doses of levodopa from ingestion of high-protein foods by two hours.

Dopamine Agonists

Dopamine agonists are a class of drugs that directly stimulate dopamine receptors in the brain. They mimic the action of dopamine, alleviating PD symptoms by bypassing the need for dopamine production.

Dopamine Agonists: Pramipexole (Mirapex®), Ropinirole (Requip®), Rotigotine transdermal patch (Neupro®), Apomorphine (Apokyn®)

Benefits: Dopamine agonists are often used as an initial therapy or in combination with levodopa. They can reduce motor symptoms, and their long-lasting effects help manage motor fluctuations better than levodopa alone.

Side Effects: Dopamine agonists may cause side effects such as nausea, dizziness, daytime sleepiness, and impulse control disorders, including compulsive behaviors like gambling or binge eating.

Special Note: While most dopamine agonists are for everyday use, apomorphine is an injectable dopamine agonist specifically developed to use as needed to treat "off" episodes. Older people may be more sensitive to the side effects of dopamine agonists.

Monoamine Oxidase-B (MAO-B) Inhibitors

MAO-B inhibitors work by blocking the enzyme monoamine oxidase-B, which is responsible for breaking down dopamine in the brain. By inhibiting this enzyme, MAO-B inhibitors increase dopamine levels and improve motor function.

MAO-B Inhibitors: Selegiline (Eldepryl®, Zelapar®), Rasagiline (Azilect®), Safinamide (Xadago®)

Benefits: MAO-B inhibitors can be used as monotherapy in early-stage PD or in combination with levodopa to prolong its effectiveness. MAO-B inhibitors may be useful for people with PD who experience extreme fatigue but may cause others to feel overstimulated.

Side Effects: Common side effects include insomnia, gastrointestinal disturbances, and dizziness. When used with some other antidepressant medications, MAO-B inhibitors increase the risk of developing serotonin syndrome, a potentially life-threatening condition. Risk for hypertensive crisis (extreme high blood pressure) is also increased if a person consumes foods high in tyramine (cured meats, aged cheeses, red wine) while taking an MAO-B inhibitor.

Catechol-O-methyltransferase (COMT) Inhibitors

COMT inhibitors are drugs that inhibit the enzyme catechol-O-methyltransferase, which breaks down levodopa into inactive ingredients. By blocking this enzyme, COMT inhibitors prolong the effect of levodopa and reduce fluctuations in motor response.

COMT Inhibitors: Entacapone (Comtan®), Tolcapone (Tasmar®)

Benefits: COMT inhibitors are often used as adjunctive therapy to levodopa to enhance its effects and reduce wearing-off fluctuations. They can provide a more stable control of motor symptoms.

Side Effects: COMT inhibitors may cause diarrhea, and urine discoloration. Tolcapone should generally be avoided due to the risk of liver toxicity. Close monitoring of liver function should occur in persons taking tolcapone.

Anticholinergic Medications

Anticholinergic drugs work by blocking the action of acetylcholine, a neurotransmitter that is overactive in the brains of individuals with Parkinson disease. By reducing acetylcholine levels, anticholinergic drugs help balance neurotransmitters and alleviate tremors and rigidity.

Anticholinergic Medications: Trihexyphenidyl (Artane®), Benztropine (Cogentin®)

Benefits: Anticholinergic medications are primarily used for controlling tremors in PD patients. They may be helpful when tremors are the dominant symptom and in younger patients with fewer motor fluctuations. These medications can also be helpful to reduce drooling.

Side Effects: Common side effects include dry mouth, blurred vision, constipation, and cognitive impairment. Older people may be more susceptible to these adverse effects.

Amantadine

Initially developed as an antiviral medication, amantadine was later found to have beneficial effects in Parkinson disease. Its exact mechanism of action in PD is not entirely understood, but it is believed to enhance dopamine release and reduce excessive glutamate activity in the brain.

Amantadine products: Symmetrel®, Gocovri®

Benefits: Amantadine is often used to manage dyskinesias associated with levodopa use, providing relief from involuntary movements.

Side Effects: Common side effects include livedo reticularis (a skin condition), confusion, and hallucinations.

Personalized Treatment

The management of Parkinson disease is complex, and no single medication suits all patients. The choice of treatment depends on various factors, including the patient's age, disease stage, symptom severity, comorbidities, and lifestyle. In many cases, a combination of medications is necessary to optimize symptom control while minimizing side effects.

It is crucial for patients to work closely with healthcare providers to develop personalized treatment plans that address their unique needs. Regular evaluations and adjustments may be required as the disease progresses.

Looking to the future, research continues to explore new medication delivery systems, new receptor targets and most importantly, therapies with disease-modifying potential.

In conclusion, medications play a vital role in managing Parkinson disease and improving the quality of life for patients. Levodopa remains the cornerstone of treatment, but a variety of other drugs, including dopamine agonists, MAO-B inhibitors, COMT inhibitors, anticholinergic medications, and amantadine, offer valuable options to address different symptoms and individualize treatment regimens.











Using MAPS — to Find Her Way

An Interview with Lynhon Stout by Anne Scherer

We shared a cup of coffee at a small neighborhood cafe and I became enchanted by Lynhon Stout. It is easy. A widow since January 21, 2021 she speaks of her love for Dave and you are part of a fairy tale romance.

A journey to travel together

Dave died of melanoma but had been diagnosed with Parkinson's in August, 2012. He had a hip replacement and his sister in- law noticed he could not raise his leg. A neurologist concurred with her suspicion that he had Parkinson's. Lynhon cried but Dave quietly accepted the journey they would travel together.

Support Group Help

The Support Group at Mercy hospital where they met together and then separately, as those diagnosed with PD and those who are caregivers, was a big crutch for them. Lynhon needed more information. She studied Parkinson's online and written materials by APDA trying to equip her mind and soul for what might come. The plot thickens when six months after his hip surgery, Dave had a heart attack. Afraid to do bypass surgery on him, the doctors put in stents, which worked. In fact, both Lynhon and Dave returned to work. Dave did retire as his Parkinson's progressed and then, as life would have it, he had a second heart attack. At this point, Lynhon also retired, not wanting to leave him alone. It was hard for her as she had created the Iowa Foster and Adoptive Parents Association and was Executive Director. Although not easy to walk away, Dave was her only focus.

Lynhon and Dave's Love Story

It was a second marriage for both of them. They had known each other for ten years through their work and were married for 28 years. The many decisions they now had to make, Lynhon says without reservation, love drove them all. One decision was to live life fully and together. They traveled, going on thirteen cruises. The arrangements she had to make to facilitate his needs were Herculean. He was mobile until the last four years when he required a wheelchair, walker and medical apparatus. These were just another type of baggage for Lynhon, the master planner.

Symptoms Progressed

By 2019, the Parkinson's was really progressing. Dave was deficient in short term memory and executive functioning, among other signs of progression.

Therefore, he did not qualify for deep brain stimulation. Further, he lost his driving privileges and that was a traumatic turning point for him. It was at this time, with his progression so obvious and DBS not available that they opted for the Duopa Pump. This would deliver Levodopa continuously into the lower intestine.

He got three cartridges of medicine a day which had to be kept cold and at a specific temperature. When they traveled, Lynhon made sure the cartridges were properly chilled. Dave wore the required pump via straps which held it in place. Normally that would be that, However, this was Dave, a very stylish dresser. So he had sixteen guitar straps (they realized these were more comfortable) to match his outfits.

Another Diagnosis

Dave participated in ADPA sponsored Parkinson's dance. He also began boxing and loved it.

Punching was a great frustration reliever. However, progression is inevitable, and he would fall often, Then, in early January of 2021 he was in extreme pain. They



called 911 and Dave was taken to the hospital where they discovered metastasized melanoma throughout his body. Within a short time, he couldn't swallow, but he refused a feeding tube or any heroic measures. Lynhon took Dave home with hospice care. He died four days later.

Using MAPS to find her way

And now what? She had helped with his bathroom needs, watched him constantly, given medications, supervised meds, food and all else that was Dave. She had been a CAREGIVER! What was her purpose now? She had not left him. She had lived her moments to make his life less stressful. She was alone and if she had been able to think of a new way to live life, there was Covid.

Being Lynhon, she searched and found her niche. She is beyond active in the Grand Living Tower support group known as MAPS (Motivated Active Parkinson's Support). They are her family now and they give her purpose and meaning.

Her love journey continues in the activities of this group. Her caretaking purpose isn't gone. It's transformed into her love and guidance through her work with MAPS, where she shares their journey and benefits others as they search for support.

APDA volunteer Anne Scherer is a retired tax consultant and business owner living in West Des Moines.

About MAPS: Motivated Active Parkinson's Support

MAPS is the largest Parkinson's support group in lowa.

More than 100 people with Parkinson's and their caregivers participate in the group.





Each month the support group is catered by Audrey Macri for a free will donation.

Find a support group near you.

Find a group that meets in-person or virtually, to gain education and meet others who are on a similar journey by visiting our website:

www.apdaparkinson.org/iowa

Thinking of starting a support group in your area?

If you need assistance or are interested in starting a support group in your area, please contact Susan Callison, APDA Iowa Program Coordinator at (515) 782-4386 or apdaiowa@apdaparkinson.org.

Planned Giving

The Gift That Costs Nothing Today

This article is provided courtesy of the Mid-lowa Planned Giving Council and the St. Louis Chapter of APDA

We want to recognize those who are caretakers, spouses, siblings, friends, children and grandchildren living with a loved one who has Parkinson's Disease. Pausing and taking a moment to simply offer gratitude is something we probably do not do enough.

Thank you. You matter to the American Parkinson Disease Association (APDA). Your charitable giving and philanthropic support of APDA lowa means so much to this chapter and to our national organization.

We are fortunate to hear from many families and friends of loved ones when they seek resources, fellowship, and support. Something we hear a lot is "I wish I could do more." Many families feel they do not have the capacity to be as generous as they would like.

The rest of this article is meant to serve as a resource for some ways to support APDA lowa that you may not be aware of. Most of these ways to give cost you nothing today.

In fact, there are many ways you can plan for the financial security of your loved ones and make a significant contribution in the fight against Parkinson's Disease. "Planned giving" is an encompassing term to describe one of three types of charitable giving: **gifts in your will or trust, gifts that produce income, and beneficiary designations.**

Gifts in your will

- You already know that creating a will or living trust is
 a smart way to provide for your family and loved ones,
 but did you know you can also document a gift to the
 American Parkinson Disease Association (and other
 charities) in your will? When you document APDA in
 your will, it does not cost anything, and you can change
 your mind or the gift amount there is no minimum,
 and gifts of all sizes really do make a difference. Setting
 up a charitable gift through a will or living trust is the
 most common way donors decide to give!
- Here is a sample of the quick and easy language to include.
- I give to the American Parkinson Disease Association lowa Chapter. located in Ankeny, lowa (insert specific dollar amount or percentage) ______ in support of its full mission. Federal tax identification number: 13-1962771.





Beneficiary designation

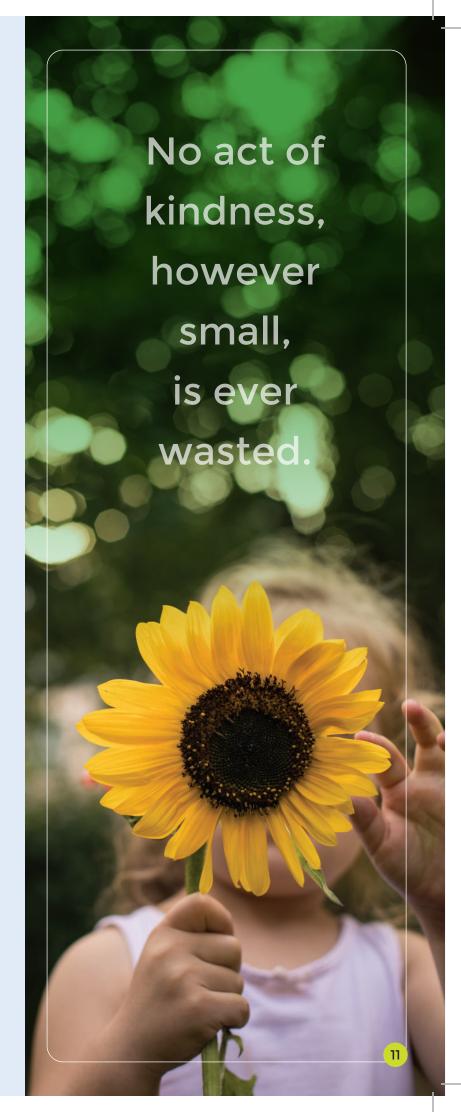
Another gift type which costs nothing is to assign APDA as a beneficiary designation. You can complete these gifts on a financial or chronological timeline which works for you. Examples include

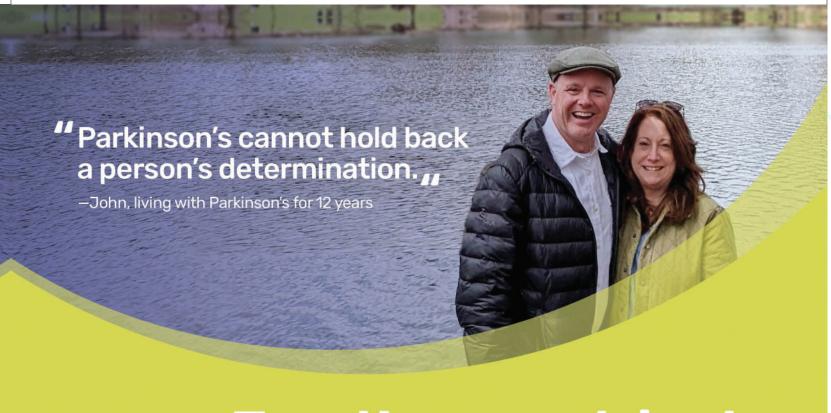
- Life insurance policies
- Bank or brokerage accounts
- · Certificates of deposit
- Donor advised funds
- Individual retirement accounts

Qualified Charitable Distribution (QCD)

It's possible to support APDA through your IRA. If you are 70½ years old or older, you can give any amount (up to a maximum of \$100,000 per year) from your IRA directly to a qualified charity such as the APDA without having to pay income taxes on the money. Gifts of any value (\$100,000 or less) are eligible for this benefit, and you can feel good knowing that you are making a difference at APDA. This popular gift option is commonly called the IRA charitable rollover, but you may also see it referred to as a qualified charitable distribution, or QCD for short.

- → Make a difference today and save on taxes.
- → Want to learn more? Speak to your tax advisor, attorney, or financial planner.
- → Thank you again for all you do!





Together, we strive to make every day icONic

Stay connected at **BeicONicwithPD.com**



Every day, we're inspired by the determination and spirit of people with Parkinson's disease (PD) as they strive to live their lives to the fullest.

That's why at Supernus, we're committed to:

- Sharing the icONic voices of people with PD
- Partnering with the PD community
- Bringing innovative PD treatments to the market







Fall 2023 Programs

APDA Parkinson Education Program

Is it PD or is it Aging?

Dr. Rebecca Gilbert, **APDA Medical Director**

Wednesday, Oct. 11 – 4 p.m.

Meadowview of Clive 3300 Berkshire Pkwy Clive, IA 50325





Scan to register

APDA Iowa Burlington Parkinson's Conference

Strategies to Live Well with PD

Thursday, Oct. 19, 1-4 p.m.

Southeast Iowa Regional Medical Center Wellness Plaza 1221 S Gear Ave.

West Burlington, IA 52655 Clive, IA 50325





Scan to register

Eastern Iowa Conference

APDA Iowa Presenting Sponsor

Dr. Rebecca Gilbert, **APDA Medical Director**

Thursday, Oct. 12 9 a.m. - 4 p.m.

St. Andrew's Presbyterian Church, or attend virtually 140 Gathering Place Iowa City, IA 52246



Scan to register





2nd Annual NW Iowa **Parkinson's Conference**

Thursday, Oct. 26 - 12-5 p.m.

Lakeshore Center at Okoboji 1864 Highway 86, Milford, IA 51351

Visit www.apdaparkinson.org/iowa

SAVE THE DATE

NOV. 8-9

Smart Home Demo

Woodlands Creek 8308 Colby Pkwy Urbandale, IA 50322 **MONDAYS** 6:30 p.m.

Sep. 11 – Oct. 16 Nov. 6 – Dec. 11

PD Moves Dance Classes

Helpful Tips

For Living Well

Amanda Landsbaum MS, OTR/L

Managing Parkinson's medication is a common topic of discussion. It's very important to take your Parkinson's medications on time, every time and not miss a dose. I often hear people say they can remember the morning and evening doses when they are at home, but it's tough to remember their mid-day dose when they are out in the community.

The following strategies may be helpful for those midday doses:

- Bring a small pill box or use a keychain pill holder to store a few extra pills
- · Carry a water bottle when you are away from home
- Set your phone alarm for your dosage times. Or if you prefer, wear a smart watch with alarm settings. These can be audio or vibration if you prefer a silent alarm.

Making sure you take your mid-day doses will help you stay on a regular schedule and manage your symptoms better. Talk to others and find out what strategies work for them. Making these small changes in your routine can lead to big improvements.











A new study that investigates the effect of two interventions on respiratory control in persons with Parkinson's disease is beginning. Participants with Parkinson's disease will complete a respiratory strength training protocol and a singing protocol for four weeks each, five days per week. Data on respiratory pressure, cough strength, and measures of wellbeing will be collected before, during, and after the interventions. Additional screening will take place during the first study visit or call. Please call the Neurophysiology lab for more information: 515-294-5476 or jbrown2@iastate.edu.

*If posted on social media, please include the following statement:

Your privacy is important. Please do not comment on or tag others in this post. Instead, please contact the researchers directly if you are interested in participating. If you know someone who may be interested, please give them our contact information.



APDA Publication **Request Form**



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Check all APDA Publications below you would like to receive. Check the box whether you would like to receive them by: mail or email.		
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☐ Fatigue and Parkinson's Disease	☐ Emergency Contact ID Card	
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☐ Constipation and Parkinson's Disease	☐ Communicating about Off Episodes	
☐ Cognitive Changes in Parkinson's Disease	☐ Medications to Avoid	
Parkinson's Disease and Oral Healthcare	■ Medications Approved	
☐ Understanding Bladder Symptoms	Livelt! Magazine	
Living Well with Parkinson's Disease - 10 Things You Can Do Now		
Addressing Mental Health and Treatment with your Doctor		
☐ Make Your Voice Heard! Healthy Communication and Parkinson's Disease		

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Parkinson's Roadmap for Education and Support Services (PRESS)

Virtual PRESS:

January 10 - February 28, 2024 Wednesdays: 11:30 a.m.-1 p.m.

In-Person PRESS:

April 10 - May 29, 2024 3-4:30 pm.

Watch our email news for day and location details.

→ Sign up for email news on the home page of our website: www.apdaparkinson.org/iowa

