

4 PD &
Dementia

6 Hacks, Tips & Tricks
to improve your day

8 IMPACT
2022 in Review

PARKINSON *Pathfinder*

FALL/WINTER 2022



AMERICAN
PARKINSON DISEASE
ASSOCIATION

NORTHWEST CHAPTER

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FALL/WINTER 2022

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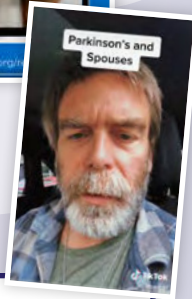
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Introducing Heidi Murdock, Fundraising Events Manager

For the past fifteen years, my career has been focused on making a difference in people's lives. I've worked for healthcare focused non-profits from Colorado to Illinois to Washington, most recently LifeNet Health.

My experiences working with the community through outreach opportunities and planning events and programs has provided me memorable and rewarding experiences where I feel I've truly made an impact. I am thrilled to join the highly successful team and community at APDA Northwest, supporting everyone's efforts and commitment to helping people impacted by Parkinson's live life to the fullest.

When I am not working, you can find me on a trail with my one-year-old son, my Irish Setter and my husband's Boston Terrier, enjoying the beautiful forests of the Northwest. I also enjoy playing tennis and spending time with my family in the garden or camping.

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Strength in optimism. Hope in progress.

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Exciting news!

APDA is expanding and adapting to meet the needs of our growing Parkinson's community.

Jean Allenbach has moved into a new Regional Director role supporting multiple chapters across the country. Kirsten Richards has been promoted to Executive Director of the Northwest Chapter. Jen Gillick continues in her Program Director role with plans to add staff to increase delivery of vital programs and resources across our five-state region. You can read about our new Fundraising Events Manager, Heidi Murdock, on the inside cover. If you have called our office recently you were likely assisted by Leah Frazier, Office Coordinator, who joined us last year and has been providing fabulous support. To accommodate this growing staff we are moving into a larger office. Please note our new address. **Helping people impacted by Parkinson's live life to the fullest remains our top priority.**

It's the season of giving and there is nothing quite as satisfying as picking out the perfect gift for a loved one. Spending some time thinking about what they might want, comparing that to what they need, and then settling on the perfect gift. However, when you or a loved one are living with Parkinson's disease, your wish list might look a little different:

APDA is working every day to fulfill these wishes, by:

- Offering a multitude of free exercise programs so that cost and lack of variety is not a deterrent
- Holding support groups and education series that focus on carepartners
- Connecting people through support groups
- Providing a financial support program to pay for unexpected expenses
- Investing in the most promising research into the cause(s), improving treatments, and finding a cure

My Wish List

- Better Treatments
- Motivation to exercise
- Support for my carepartner
- Connections with people who understand
- Financial Support
- A CURE

When you give a gift to APDA you can fulfill

a wish! When you give a gift to APDA, you are bringing opportunities for connections, wellness, education, and support directly to people impacted by Parkinson's. Maybe you will fulfil the wish of someone like Carolyn, who told us about her experience after recently attending an APDA support series for carepartners:

"I know that I am supported by some great people and a great organization. The class taught me communication skills to talk with my family and encouraged me to reach out to them and others. The course also gave me communication skills to deal with my partner and reduce my frustrations. I learned how to deal with stress using meditation techniques. Most importantly, I learned I am not alone, and I am not the first to travel this road."

Your contribution today can fulfill a wish tomorrow. You can make a gift online at apdaparkinson.org/Northwest or use the envelope in the middle of this magazine. Thank you for being such a caring supporter of people with Parkinson's!

With gratitude,

Kirsten Richards

Read how APDA programs and resources have had an impact on our PD community on pages 8-9.



Staying Active with PD: My Dad's way

By **Hanna Shigemitsu**

My father was diagnosed with Parkinson's disease (PD) in April of 2018. Before his diagnosis, he lived an active lifestyle. He was a track and field coach at a local club, he loved hiking, taking long walks, and overall being out in nature. Confronted with his diagnosis, a difficult question arose: how do you stay active with a disease that limits and takes away your mobility over time? There's no clear answer, but one thing can be said for sure, it's different for everyone.

This is my dad's story.

My dad likes cars, computers, outdoorsy things, and reading. I unfortunately did not inherit any of these interests, but we share a passion for other things, like photography. His diagnosis has never stopped him from challenging himself and doing what he wants, and I admire that about him. After his diagnosis he says that the hardest part was accepting it, but after about 10 months, he chose to fight it, rather than to let it define him. One of the ways he has chosen to fight it is through hiking. He was introduced to the Pass to Pass organization (<https://passtopass.org/> — A Hike on the Pacific Crest Trail for Parkinson's) by a local support group here in Bellevue, and his first backpacking trip was in 2019. Since then, he has regained his confidence and has been able to enjoy outdoor activities without letting PD hold him back. This summer, my dad hiked ~80 miles on the John Muir Trail with Pass to Pass. I wanted to learn more about his experience of hiking with PD. Everything from the struggles he faces, the motivation he finds, and how it impacts his day-to-day life.

How does backpacking impact you both physically and mentally?

I feel a lot less stressed when I'm backpacking! I feel so much more relaxed, and it reflects very well on my physical and mental health. Not having a constant stream of information allows me to focus on what's in front of me, one step at a time.

Multiday backpacking must be difficult on you, both physically and mentally. How do you prepare for these long and challenging backpacking trips?

To physically prepare for these trips, I make sure to stay active the weeks or sometimes months before the trips. When I know the dates I'll be hiking, as well as the route, I make sure to tailor my exercises so I know I am ready. This obviously puts me in a position where I am physically and mentally ready, but it also builds my confidence. Being confident that I will be okay on the trip and that I am ready really reduces my stress. For me, stress significantly amplifies the tremor on my right hand, which is not ideal.





"I set goals and vocalize them. I tell my peers, I tell my family, I tell my friends, I even post on my social media. This holds me accountable."

surrounded with backpackers with PD and support hikers, most of whom have someone in their family with PD. This allows me to feel my best as I tackle any hiking challenges.

Other than your daily exercise, what has helped you physically?

Physical therapy and boxing. Parkinson's makes some of the most unexpected muscles uncontrollable. I went through three months of Pelvic Floor Therapy, and it has had a significant impact on me. Currently, I regularly go to physical therapy to improve balance and reduce rigidity. I also go to a weekly boxing class for people with Parkinson's. In the class, I get to work on boxing skills but also mobility in unexpected ways. And I love having you (Hanna) helping the boxing class.

Injury is common when hiking difficult terrains. Are you not worried of injuring yourself badly when going on challenging climbs like Mt. Rainier, or a multiday trek like the John Muir Trail section hike?

I tell myself that having the right training and preparation reduces injury risk, so I focus on staying active and training instead of worrying about it. Having said that, I have had a few bad injuries. Once, I took off my micro-spikes too early, slipped on frozen dirt, and badly sprained my ankle. I was on crutches and wore a cast for 2 weeks. I also cut my chin with an ice ax because I did not have full control of my right hand holding it. Both were avoidable with more training, listening to my body more carefully, and taking precautions. I do not allow the fear of injury to stop me from moving.

Any last words of wisdom?

Create a good support system. I have worked with many healthcare providers (neurologist, dermatologist, physical therapist, massage therapist, acupuncturist, etc.) to find out what works the best to control my PD symptoms. At home, my wife prepares healthy food and reminds me to eat well (when I was diagnosed, I lost my appetite and lost ~35 lbs.). And you (Hanna) help me box at home and at the gym.

This is how my dad stays active with PD. I'm lucky enough to be involved in his journey and his fight against PD and look forward to continuing to support him. I hope that his story has empowered and inspired others with PD to stay active and fight.

Climbing mountains and backpacking for days is difficult to say the least. I procrastinate a lot. What do you do to hold yourself accountable?

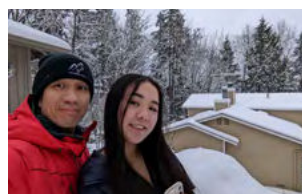
I set goals and vocalize them. I tell my peers, I tell my family, I tell my friends, I even post on my social media. This holds me accountable. Plus, vocalizing them and making my goals public draws attention. I get to meet fellow PD hikers, gain support from my friends, and get to share my story and inspire others. I never feel lonely. Setting crazy, ambitious goals, like summiting Mt. Rainier, which I don't even know if I will be able to achieve, allows me to do things I never thought were achievable. In preparation to climb Mt. Rainier, I summited Mt. St. Helens and Mt. Adams, which I didn't think was possible a year ago.

Your right side is the side most impacted by PD, what are some things you incorporate into your daily exercise that help you with mobility on your right side?

I always make sure to stretch after my exercise because with PD, my muscles tighten up a lot more than they used to. Another thing that has helped me a lot is exercising to full execution and with all of my power. When I carelessly jog, my right arm isn't swinging, and my right leg isn't lifting. I am almost dragging my right foot. This makes it more difficult and frustrating to run, not to mention it is not what we want. When I sprint and really put my mind to it, my body tends to revert back to its original muscle memory, and I can balance better and there is no tremor. Lastly, limited mobility on my right side is inevitable. I exercise in a room with a very big mirror. That way, I can consciously look at my movements and make sure my right side is engaged and moving the same or as close to the same way as my left.

How do the people you surround yourself with during your hikes impact you?

It is very important that I am comfortable during my hikes. Surrounding myself with friends that support me and don't judge me allows me to feel safe and that reflects on my physical wellness. For example, during Pass to Pass, I am



Hanna Shigemitsu is a high school senior, interested in pursuing pre-med in college. She actively volunteers in her local community to support Parkinson's.



Parkinson's Disease *and* Dementia

By **Dr. Arif Khan, MD**

Within the Parkinson's disease (PD) community, much is understood about the physical distress caused by the disease. Tremor, muscle rigidity, balance impairment and slowness of movement are all common symptoms even though they impact everyone differently. A lesser known and not as widely understood symptom that can be a part of PD is cognitive decline.

As PD progresses, many individuals experience significant changes in their abilities to think and process, including difficulties with problem-solving, attention span, memory, as well as planning and following through on the steps needed to complete a small task. As such, new research is being conducted to better understand the link between PD and cognitive decline that may lead to dementia.

What Is Dementia In Parkinson's Disease?

Dementia is an umbrella term for the decline in memory and thinking skills to a level that interferes with normal day-to-day function. There are congenital and hereditary forms of dementia, as well as acquired forms that are often the result of an accident causing head trauma or an infection of the brain. However, the most common are degenerative forms of dementia, including Alzheimer's Disease, Parkinson's Disease Dementia, and Dementia with Lewy Bodies.

In our PD patients, there is often particular concern of whether they have Parkinson's Disease Dementia (PDD) or Dementia with Lewy Bodies (DLB). They are similar diseases characterized by patients having difficulties with mobility and cognition. What is different between PDD and DLB is the timing of when these difficulties occur. DLB patients develop cognitive issues much sooner than PDD patients, sometimes before they even show signs of mobility issues. Both diseases are thought to be caused by the abnormal accumulation of a protein called alpha-synuclein in the brain causing clumps called Lewy bodies. The location of these Lewy bodies can differ between PDD and DLB, leading to earlier development of dementia (the rule of thumb is within one year of developing movement issues). Because of the similarities between PD, PDD, and DLB, current thinking in the medical community is that they should be viewed as related diseases that fall along a continuum of Lewy body disorders.

Symptoms of Dementia

It is important to note that the rate of dementia, just like the rate of motor decline, may vary between patients. In addition, the types of cognitive difficulties may also vary.

Some of these difficulties include the following:

- Orientation to time, date, and place
- Short and long-term memory issues
- Confusion
- Forgetfulness (leaving stove on, misplacing items)
- Keeping focused when carrying out a task
- Problem solving
- Multitasking
- Word finding difficulties
- Hallucinations (Seeing or hearing things that are not real)
- Delusions (Having strange, false beliefs that can lead to suspicion, distrust, paranoia)
- Visuospatial issues (Depth perception, locating objects, navigating when driving)

Over time, these difficulties can significantly impact a patient's happiness, quality of life and ability to live independently. They can also take a toll on the caregivers and surrounding loved ones.

Treating Dementia in PDD & DLB

Some of the problems caused by dementia are fortunately manageable by medication and behavioral strategies. Medications used to improve cognitive function in PDD and DLB are the same ones used for other dementias such as Alzheimer's disease, including donepezil, rivastigmine and memantine. While these medications can be helpful, they ultimately do not cure or slow down the progression of dementia. More research needs to be done to develop more effective treatments.

The SHAPE Trial is a clinical research study showing some promise in treating the cognitive decline. Currently in Phase 2, the study aims to determine whether the investigational drug fosgonimeton (ATH-1017) is safe and effective in improving cognitive symptoms of PDD and DLB. Fosgonimeton has been

SHAPE TRIAL

The SHAPE Trial is a Phase 2 Study of an investigational drug for the treatment of Parkinson's Disease Dementia and Dementia with Lewy Bodies.

Successful clinical trials need volunteers! Participants are being recruited by the Northwest Clinical Research Center, Evergreen Healthcare Research, and Inland Northwest Research.

You or someone you know may be eligible if you:

- Are **between 40 and 85** years of age
- Have experienced **memory problems** and have been diagnosed with **Parkinson's Disease Dementia** or **Dementia with Lewy Bodies**
- Have a **reliable support person or caregiver** who is willing to participate in study visits, report on daily activities and oversee or help you with taking fosgonimeton

Additional info:

Study participation and study drug are free to all participants enrolled in the study.

You may receive a stipend to compensate for time and effort for study participation including meals, travel, etc.

Northwest Clinical Research Center,
Bellevue WA

CONTACT: Kimberly Wheeler 425-453-0404
recruitment@nwcrc.net

PRINCIPAL INVESTIGATOR: Dr. Arif Khan

Evergreen Health Research, *Kirkland WA*

CONTACT: Sameera Hasan 425-899-5385
evergreenresearch@evergreenhealth.com

PRINCIPAL INVESTIGATOR: Dr. Daniel Burdick

Inland Northwest Research, LLC,
Spokane WA

CONTACT: Melissa Bixby 509-960-2818
Mbixby@inwresearch.com

PRINCIPAL INVESTIGATOR: Dr. Jason Aldred

designed to help stimulate brain cells to function better, to form new connections to other cells, and to ideally prevent cell death in the brain leading to dementia. The drug, which is also being studied in Alzheimer's Disease, represents a new approach to treating dementia in PDD and DLB, by repairing brain cells and rebuilding brain networks.

Conclusion


Dementia impacts many patients with PD, leading to difficulties with managing the complexities of day-to-day life. Research studies, such as the SHAPE Trial, are being conducted in hopes of developing treatments that may repair the brain and improve cognitive function.



Arif Khan, MD is the Medical Director at Northwest Clinical Research Center in Bellevue, Washington. Dr. Khan is a Board-Certified Psychiatrist and an Adjunct Professor of Clinical Medicine at the Pacific Northwest University of Health Sciences. Dr. Khan has been conducting clinical trials in the greater Seattle area since

1984 and founded the Northwest Clinical Research Center in 1995. He has been the Principal Investigator in over 600 clinical trials. In addition, he has published more than 175 scientific papers in leading medical journals.

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Hacks, Tricks and Medication Tweaks to Improve your Movement and your Day

By **Dr. Rebecca Gilbert, MD, PhD**
& **Dr. Joseph Friedman**

In April of 2021, Dr. Rebecca Gilbert, APDA Chief Scientific Officer hosted Dr. Joseph Friedman, a movement disorders neurologist and the Medical Director of the APDA Rhode Island Chapter and Information & Referral Center, for a conversation about small changes in your routine that can have a big impact on quality of life, which you can view [here](#). He shared a wealth of hacks, tricks, and medication tweaks that can help improve your movement and your day – everything from how to deal with a runny nose caused by PD to tips for weight gain.

Many of Dr. Friedman's tips are things he's learned and observed in his own patients over the years. Knowing how resourceful people can be when they need to be, Dr. Gilbert reached out to our Parkinson's disease (PD) community – people with PD and their care partners – for the ways that they have found to improve their quality of life. Sometimes a small adjustment can make a tremendous difference so we are eager to share some of the great answers and ideas she received so we can all learn from each other.

Swapping strategies to overcome the challenges of PD is one of the wonderful benefits of joining a [support group](#) or an online patient community such as [Smart Patients](#). To find a support group near you, please visit the APDA Northwest website. No group in your area? We can help you start one! Just contact us for help.

Tips & Tricks for Living with Parkinson's Disease

(Some of the answers below have been edited for clarity)

Diet and Nutrition Tips:

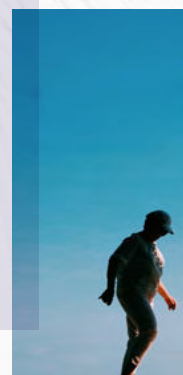
- I eat healthy meals.
- I try to stay hydrated.
- I remove the stress and anxiety around taking medication and eating.
- Nausea takes away appetite and contributes to weight loss. So, if there is nausea, make sure that you eat food with your medications.

APDA tip: Use keyword "[nutrition](#)" to search for helpful information on our website, including [a recent blog post](#) about the MIND and Mediterranean diets for people with Parkinson's.

Exercise Tips:

- As always, I continue to exercise!
- I space out my physical activity throughout the day and take it easy in the evenings.
- I swim about four times a week, about 30 minutes each time and feel this is essential for me. I have a lot of back pain that makes it hard for me to walk any distance, so swimming is a great option for me.
- I always remember to keep moving – especially when the fatigue seems overwhelming.
- I try to listen to my body and exercise during the peak of medication effectiveness.
- I start the day with exercise.
- When I start feeling off, I get up and do some exercises or go for a walk.
- If my leg gets tight, I focus my mind and can consciously relax it.
- I invested in a really good pair of golf shoes that improved my stability when I play golf. They were more expensive than a lot of golf shoes, but not as expensive as having to have another hip surgery from falling!

APDA tip: Check out the [Let's Keep Moving With APDA video series](#) on Parkinson's fitness advice, and [Be Active & Beyond](#), our exercise booklet made specifically for people with PD.





Medication Tips:

- A pill container organizes the pills I take at different times of the day.
- My doctor told me to take half-pills at more frequent intervals, to better cover the day.
- My Smart Watch can be programmed so I don't forget my medication doses.
- I use Miralax for constipation and it works beautifully!
- In the evening, my mouth can be dry from the medication. I don't want to drink a lot of liquid at that time, so I suck on an ice cube.
- I use Psyllium for constipation.
- I use an online pharmacy which helps me keep my prescriptions organized.
- Taking my medications on time makes all the difference to me.
- I take an extended-release medication just before bedtime which helps me through the night.

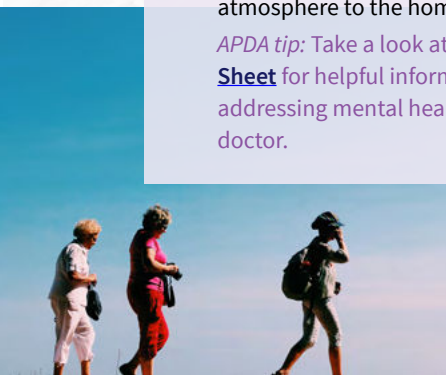
APDA tip: Keep our [Medications to Avoid](#) list handy, as there are certain medications that people with PD should not take, or should be used with caution.



Mental Health Tips:

- Every day is different. I try to listen to my body. If I feel extra tired, I don't push myself.
- I remind my spouse with PD to relax and be realistic.
- I stay calm.
- I try to just have a good attitude.
- As a care partner for someone with PD, I try to keep positive thoughts going and encourage my wife to exercise.
- I try to take each day as a new day and start each day on a positive note – even though at times it is difficult.
- I nap for at least 20 minutes a day to get rejuvenated.
- I make sure that there is a lot of lighting around the house as well as music. This gives an upbeat atmosphere to the home.

APDA tip: Take a look at our [Mental Health Fact Sheet](#) for helpful information and advice on addressing mental health concerns with your doctor.



Other:

- I stay as busy as I can!
- I schedule bathroom trips.
- We use side rails and pillows to prevent injury from active dreaming (REM behavior sleep disorder).
- When my feet get stuck, I count out loud – this often works to get unstuck. Once I'm moving forward, I am doing well. I still fall more than I like, usually backward. I've learned to just never go even one step backward without hanging on to something, like one of the many grab bars I've had installed.



Tips and Takeaways

- Small changes in your routine can have a big impact on quality of life in PD
- [Joining a support group](#) is a good way to hear about the strategies that others use to overcome the challenges of life with PD, and share some tips of your own
- Support and resources aren't just for people living with Parkinson's – explore our [resources for PD care partners](#) as well
- You can hear about more helpful ideas in [our recent conversation with Dr. Friedman](#)



For this year's accomplishments we have consulted actual feedback from our most valuable critics ... YOU!

This course has been the **best I have ever attended and for the first time I haven't felt alone and incompetent.** My fellow attendees and our leaders have given me hope and important tools to deal with the challenges of taking care of my husband. Thank you for finding room for me.

Motivated

Information



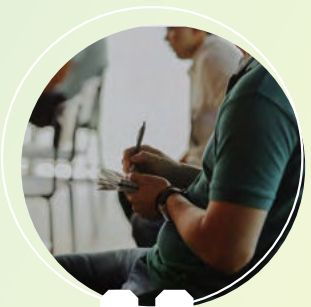
Innovative



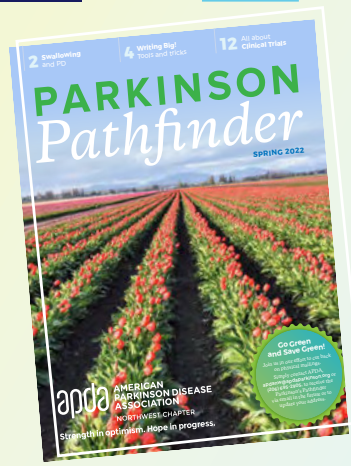
Purposeful



Patient-Centered



I have just completed reading the Spring *Pathfinder* from cover to cover, and I found it excellent in all its aspects!



I found the **group and the leader very supportive.** Every time I attend an activity associated with Parkinson's, I either **learn something or reinforce something I already knew.**



APDA and its volunteers and supporters really ROCK! After 14 years with Parkinson's carving our lives, Neal is in an advanced stage. We are ever so grateful for the annual support/scholarship stipend from APDA.

I know that I am supported by some great people and a great organization. The class taught me communication skills to talk with my family and encouraged me to reach out to them and others. The course also gave me communication skills to deal with my partner and reduce my frustrations. I learned how to deal with stress using meditation techniques. **Most important I learned I am not alone and I am not the first to travel this road.**

We really appreciate the **specificity of the discussion** — particular symptoms and causes and treatments. Also the patience in answering so many questions!

Best PD presentation I've ever seen! So clear and comprehensive.



Well done!
Your group is a Godsend.



THANK YOU so very very much! I have recently realized how I've neglected myself due to this Parkinson journey. **You can't do it alone** you need to be able to share with others and they with you so I truly from the bottom of my heart thank you you're a savior!



Action

Attentive



Advocate

Creative



Caring

Connected

Together



Thoughtful

Teamwork



Today's group was especially helpful to me. My husband and I are dealing with almost every symptom / situation described by the others in the group, but it is still **reassuring that we are not alone on the PD trip through life.** And the ideas/suggestions are sometimes life changing. So thank you. **You are the right person in the right place, doing the right work.** And I am grateful for you.

It's clearly evident how much each one of you care. Thru volunteering with you I was able to find resources and a community to help both myself and my family in a time of turmoil and change. Thank you from the bottom of my heart.



I'm feeling **empowered to live life more intentionally...** learning to balance my husband's needs and my needs... learning not to let caregiving totally consume me - my time, energy, thought life, etc. Using the action plan to schedule time for me to do things that feed my soul... Helps me be a healthier, more proactive caregiver.

Thank you for setting up these fun AND relevant classes. It was very good that you take the classes with us rather than just leaving everything to the instructors. It shows your commitment to the program.

This was an OUTSTANDING program. The leader was excellent. She connected with the participants and got great participation. Lots of ideas from Andi and class participants. Please continue to offer this program. Occupational therapy is very important in maintaining fine motor skills and improve the quality of lives of persons with PD.



Exercising Safely with Parkinson's disease and Orthostatic Hypotension

By **Dr. Jennie Alex**

Have you ever gotten out of bed too quickly and felt lightheaded for a few seconds? This phenomenon is called orthostatic hypotension (OH) which is a drop in blood pressure that occurs moving into standing.

Occasional, brief episodes of OH are not concerning. However, when the symptoms are persistent, they can interfere with quality of life, contribute to falls, and limit exercise that is vital for Parkinson's disease (PD)⁽²⁾. It is estimated that 30-60% of individuals with PD have OH, however, it is only symptomatic in 18% of these individuals⁽⁷⁾. While OH is more common with advanced disease, it can also be present in early stages.

Research has demonstrated that when individuals with PD monitor blood pressure and take a staged approach to control OH, they experience improved motor function, balance, and cognition⁽²⁾.

Role of the Autonomic Nervous System with Blood Pressure Regulation

Blood pressure is controlled by the **autonomic nervous system (ANS)**. The ANS regulates involuntary body functions such as blood pressure (BP), heart rate, respiration, urination, and digestion. Our ANS is made up of two systems that work in balance: sympathetic ("fight or flight" increases BP) and parasympathetic ("rest and digest" decreases BP).

What happens to blood pressure when standing up?

Baroreceptors are pressure sensors located in the walls of blood vessels in the heart. When we stand up, the force of gravity causes blood to pool in the lower extremities, reducing blood flow back to the heart. Baroreceptors quickly sense this drop in BP which results in activation of the sympathetic nervous system. Constriction of peripheral vessels pushes blood back to the heart, while increased heart rate and contractility restores blood flow to the brain and other vital organs.

What Is Orthostatic Hypotension?

Orthostatic hypotension is a **sustained** reduction in blood pressure that occurs within three minutes of moving into standing. It is defined as a **drop in systolic pressure (top number) of ≥ 20 mmHg OR a drop in diastolic pressure (bottom number) of ≥ 10 mmHg**.

Symptoms of OH include:

- Dizziness or lightheadedness
- Weakness or leg buckling
- Fainting
- Nausea
- Visual disturbances
- Confusion
- "Coat hanger pain" (pain in the upper back and neck)

Note: symptoms occur when moving into a standing position and should improve sitting or lying down.

OH can be worse with the following conditions:

- **Dehydration**
- **Alcohol**
- **Heat** (hot showers, warm weather)
- **Morning**
- **Postprandial Hypotension** (with 2 hours of carbohydrate-rich meals)

What Causes Orthostatic Hypotension in Parkinson's Disease?

There are two primary causes of OH in individuals with Parkinson's disease:

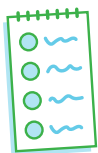
1) Autonomic Dysfunction and PD

In PD, there are Lewy bodies in the substantia nigra that cause degeneration of dopamine-producing neurons. This dopamine deficiency results in the motor impairments commonly associated with PD including tremor, slowed movements, and rigidity. In PD, Lewy-body pathology is also found in autonomic structures, causing dysfunction and degeneration of the ANS. Autonomic symptoms include OH, constipation, urinary issues, difficulty with temperature regulation, and sexual dysfunction. Orthostatic hypotension that is the result of the disease process itself is referred to as neurogenic orthostatic hypotension (nOH).

Note on Supine Hypertension: Individuals with nOH who experience a drop in BP in standing, may also experience elevated BP while lying flat. Supine hypertension is defined as systolic BP ≥ 140 mmHg, diastolic BP ≥ 90 mmHg after lying down for 5 minutes. (often asymptomatic)

2) Side Effect of Dopaminergic Medication

Orthostatic hypotension also occurs in PD as a side effect of Levodopa and Dopamine Agonists.



Practical Steps To Manage Orthostatic Hypotension

Managing OH is not “one size fits all” and requires a coordinated approach from your medical team. It is important to discuss these recommendations with your physician, especially if you have any underlying heart disease, hypertension, or kidney disease.



Step One: Monitor Your Blood Pressure

Orthostatic BP Monitoring in the Clinic or at Home

- Lie down for 5 minutes and take a BP reading
- Stand up and take a BP reading after 1-3 minutes

Keep a Blood Pressure Log

- Home BP logs provide valuable information to your medical team
- With a low reading, note medication timing and contributing factors (ex: big meal, exercise)

24 Hour Ambulatory Blood Pressure Monitoring

- With complex OH cases, your MD can order this to measure BP on a continuous basis



Step Two: Address Aggravating Medications

It is important to work with your neurologist, cardiologist, primary care physician, and urologist to determine if there are any medication adjustments that would assist with OH management.

• Dopaminergic Medications

Your neurologist may adjust the dosage or timing of your PD medications. Levodopa (Sinemet, Rytary), Dopamine agonists (Ropinirole, Pramipexole), and Selegiline all lower BP.

• Antihypertensive Medications

Individuals who were on antihypertensive medication prior to the onset of PD, may need to reduce or discontinue these medications. Examples include Antihypertensives (Metoprolol, Lisinopril, Amlodipine) and Diuretics (Lasix)

• Urinary Medications

Alpha-1 adrenergic blockers used to treat BPH also lower BP (Terazosin, Doxazosin, Tamsulosin, and Alfuzosin)



Step Three: Lifestyle Changes

It is important to clear these lifestyle changes with your physician. Increased intake of fluids and salt may not be advisable for individuals with kidney disease, hypertension, or heart failure.

Hydration

Drink 2-3 Liters of water per day

- Purchase a 40 ounce water bottle and aim to drink 2 bottles per day
- Try to consume most of your water while at home near the restroom
- Add electrolytes to water (Liquid IV and Nuum) as directed by MD
- Try adding a splash of juice or other flavoring if you dislike plain water
- Drink 2 cups of water for every 1 cup of coffee or alcoholic beverage

Add Salt to Your Diet

- Add 1-2 teaspoons of salt per day

Compression Garments to Prevent Blood Pooling

- Elastic abdominal binders are very effective
- Bike Shorts and Spanx can be easier to manage than compression stockings

Postprandial Hypotension Recommendations (low BP after meals)

- Eat smaller, more frequent meals and avoid alcohol
- Drink two 8 ounce glasses of cold water with your meal
- Avoid refined carbohydrate-rich meals (ex: white bread, white rice, crackers, and cereals)

Supine Hypertension Considerations

- Raise the head of the bed 30 degrees (can use a wedge)
- Avoid lying flat after taking OH medications (listed below)
- MD may prescribe a short-acting antihypertensive medication at night or recommend a carbohydrate-rich snack before bed



Step Four: Prescription Medications for Orthostatic Hypotension

If the above measures do not adequately control low blood pressure symptoms, your physician can prescribe medications to treat OH. These medications included: Fludrocortisone, Midodrine, Droxidopa, and Pyridostigmine (*supine hypertension can be a side effect*).

Exercise Considerations with OH

- Drink two 8 ounce glasses of cold water before exercising (consider adding electrolytes to water as advised by MD)
- Eat a low-carb salty snack before exercising (salted nuts, nut butter, hummus)
- Consider seated rowing machine, recumbent bicycle, or swimming (compression from the water can improve OH)
- Wear an abdominal binder low and tight
- Exercise in the morning when temperatures are cooler
- Use recovery strategies when OH symptoms occur with exercise
- Sit down and perform recovery maneuvers (cross legs and squeeze leg muscles, perform upper body resistance band exercises)
- Lie down with legs elevated if symptoms persist
- Drink 500 ml (16.9 ounces) of cold water over the course of 2-3 minutes

Role of Physical Therapy with Orthostatic Hypotension Management

Individuals with PD who have symptomatic low BP in standing or a history of falling due to OH may be reluctant to exercise. This leads to deconditioning which places them at risk for more rapid progression of their Parkinson’s disease.

Physical therapists (PTs) can utilize a number of strategies to help you safely exercise with OH:

- Perform BP monitoring in the clinic and teach you how to self-monitor with exercise
- Teach you recovery strategies for when your BP drops
- Improve your safety during position changes
- Analyze your BP logs to more optimally schedule workouts
- Develop an individualized exercise routine that allows you to exercise safely
- Pelvic floor PTs can help you address urinary urgency which is a common barrier to increasing water intake

Summary

- OH occurs in Parkinson’s disease due to autonomic dysfunction from the disease process itself, and as a side effect of

dopaminergic medication

- Antihypertensive medications may need to be reduced for individuals with PD who are experiencing OH
- Keeping a blood pressure log at home can be very helpful
- Successful OH management involves a coordinated approach from your medical team along with lifestyle changes (hydration!)
- PTs can help you with strategies to exercise safely with OH



Dr. Jennie Alex works at the Parkinson’s Fitness Project in Seattle, which offers Physical Therapy, Personal Training, Group Classes and Online Exercise Training. Jennie is a

Doctor of Physical Therapy who has been working with individuals with neurologic diagnoses for 16 years. She received her certification as a Neurologic Specialist in 2015 by the American Board of Physical Therapy Specialties and is a PWR!Moves® certified therapist through Parkinson Wellness Recovery.

References:

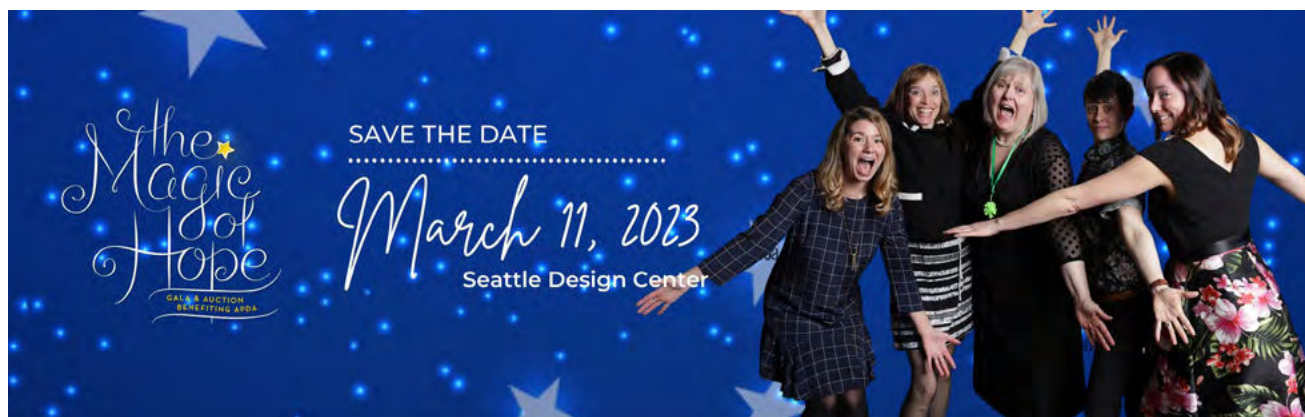
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World Parkinson Congress 2016 Dysautonomia by Dr. Horacio Kaufmann, MD.





OPTIMISM WALK

AMERICAN PARKINSON DISEASE ASSOCIATION

Back in person!

On October 1, walkers gathered in Seattle, Olympia, Bainbridge Island, and all around the Northwest in a region-wide celebration of our Parkinson's community. It was a gorgeous sunny day and spirits were high!

Optimism Walk Highlights:

- 36 fundraisers received **Circle of Optimism medals** and were recognized for **raising more than \$1,000 each**
- **Top Fundraising Team SEAYOPD** (Seattle Young Onset PD Activity group) led by Team Captain Brian Harris raised an astounding \$26,865
- **Team Tiernan** showed up in force in purple team shirts and colorful sunglasses, earning the **Largest Team Award** with 64 team members and also the **Team Spirit Award**
- **The Olympia walk raised \$7,791** in their first year
- Top individual fundraisers **Paul Herber** and **Bill Smersh** traded the lead for the two weeks leading up to the Walk, when **Paul pulled ahead for the win** with an individual fundraising total of **\$8,225**
- Our **Honoree Mike Adkinson** (of Tractor Trip for Parkinson's fame) told the Seattle crowd about his journey across 5 states and his main takeaway: "there are lots of good people between here and Minnesota!"

Thanks to all of this fabulous fundraising, we beat our goal and raised \$176,265 to help pay for local education, support, resources, and research.

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