

**4** Using an app-based  
Symptom Tracker

**6** Managing PD  
in the Hospital

**8** Overcoming  
Freezing Episodes

# PARKINSON *Pathfinder*

SUMMER 2023



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APDA Northwest  
130 Nickerson Street, Suite 300  
Seattle, WA 98109

Phone: 206.695.2905  
[apdanw@apdaparkinson.org](mailto:apdanw@apdaparkinson.org)  
[apdaparkinson.org/Northwest](http://apdaparkinson.org/Northwest)

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#### OUR MISSION

Every day, we provide the support, education,  
and research that will help everyone impacted by  
Parkinson's disease live life to the fullest.

*To be online, or to be in person.  
That is a great question.*

In today's world we can do just about everything virtually... but should we? Despite the challenges we faced during the pandemic shutdown, something unexpected happened when we dove headfirst into virtual programming. We discovered a whole new world of online connections that allowed us to reach out and engage with people like never before. Suddenly individuals from all our five states could come together in one virtual space and enjoy a Take Control education program; someone in Montana could join an exercise class taught by an



Kirsten (2nd from left) connecting with friends at the APDA Regatta

instructor in Alaska; and APDA could speak to support group attendees - no matter where they lived - to share vital resources over Zoom. This shift to virtual also opened opportunities for people who lived too far away from a support group or exercise class, or perhaps were no longer driving, to learn, connect, and get their exercise on, all from the comfort of their homes.

While virtual connections brought many of us closer together, we also discovered that it unintentionally left some people behind. Those who don't have an email address can't receive updates about the exciting virtual opportunities APDA offers, and those who lack a computer or technological savvy are unable to join an online meeting. And as wonderful as these new virtual connections are, they simply can't replace

the warmth and authenticity of face-to-face interactions. There's something special about looking someone in the eye, exchanging smiles, reading their body language to ensure they feel comfortable and welcomed, and sharing a handshake or a warm hug. It's these personal encounters that truly bring us joy and deepen our sense of empathy. Conversations flow more naturally, interruptions are less frequent, and miscommunication occurs less often.

Finding the right balance between virtual and in-person programming has become one of our top priorities. We've been working on a solution that we hope will offer an inclusive and healthy blend of both approaches. Take Control and several other education and exercise classes will remain virtual, allowing individuals from all corners to benefit from our valuable resources. Simultaneously, we are thrilled to announce that APDA will soon be visiting a community near you! Between September 2023 and August 2024, our goal is to personally visit each of our five states at least once, bringing our programs and support closer to your doorstep.

We look forward to connecting with you, whether on a screen or in person. We hope to be able to shake your hand or give you a hug... but in absence of that, a friendly hello over Zoom will do wonders.

Warm regards,

**Kirsten Richards**  
Executive Director



# Legend of The Kraken

By **A.C. Woolnough**



*Excerpted from Still on Fire, Further Reflections on a Journey Through Life with Parkinson's Disease, by A.C. Woolnough*

I have written about my dad, Bob, several times – partly because we have the Parkinson's connection, but mostly because of my admiration for him. Imagine yourself at 18 going to court and ending up on a submarine in the Pacific Ocean during WWII within a few weeks! Family lore suggests it was not entirely voluntary. Apparently after numerous run-ins with the local police while speeding through town on his Indian motorcycle, terrorizing pedestrians and other vehicles, he finally had an appearance before a local judge. After being severely chastised, he was given a choice: 30 days in the local hoosegow or sign up with the recruiter sitting at his desk next to the witness stand. The different branches of the service rotated daily, and that day was the Navy's turn. That is how Bob became a sailor. True or not, it makes for a good story.

Bob spent time late in WWII on the submarine Kraken (SS-370). The Kraken is a mythological creature in Scandinavian folklore going back as far as the 13<sup>th</sup> century. Living off the coasts of Greenland and Norway, the Kraken was powerful enough to pull ships under water. Think of the phrase, "Here there be monsters," written in blank spots of ancient maps and atlases. It is widely

believed that the legendary sea-going terror is based on sightings of giant squids (*architeuthis dux*) or some other oversized cephalopod.

Why share these stories in a column devoted to Parkinson's disease? The simple answer is Parkinson's is a Kraken and our lives are a journey on the sea of life. Most of us never see the Kraken. Some folks, friends and relatives, may see the Kraken. Others, care partners, have to deal with the consequences and aftereffects of the Kraken. Finally, some of us must battle the Kraken.

If the Kraken is a giant squid, there are some oddities to recognize. The Kraken has three hearts, all of them evil. One of them is assigned to the movement symptoms (tremor, gait, freezing, balance issues, dyskinesia, etc.); another is in charge of non-motor symptoms (loss of smell, apathy, depression, constipation, sexual dysfunction, dementia, hallucinations, pain, sleep issues, etc.); and the third heart is responsible for a lessening in the quality of life (decreased socialization, reduced ability to travel, loss of interest in hobbies and activities, etc.).

Finally, when the Kraken decides to take a bite out of the PWP with its parrot-like beak, it uses a radula (instead of a tongue) to inflict as much damage as possible – the radula being similar to a huge rasp designed to shred flesh with tooth-like barbs aimed backwards.

The Kraken does have a weakness! Their brains have a hole in the middle. Really! They are shaped like a torus (doughnut). If scientists and researchers can figure out how to exploit this potential flaw, we can defend ourselves better and maybe even eliminate the Kraken. That is why I support and encourage participation in research, education, and advocacy for Parkinson's disease. If we get better treatments and possibly a cure, our journey on the sea of life will be so much better.



**A.C. Woolnough** was an English teacher and high school principal in California, Idaho and Alaska for 37 years. Shortly after retiring, he was diagnosed

with PD—making him a second generation PWP. He became involved with the Parkinson's Foundation as a member of their People with Parkinson's Advisory Council and as a Research Advocate. He has participated in more than 25 research studies and projects. He has authored two books (*On Fire and Still on Fire*) about living with Parkinson's. He stays involved with political advocacy, raising awareness, reviewing grant proposals, leading a support group, and as a member of the OHSU patient advisory council in Portland, Oregon.



# ASK THE DOCTOR

**Dr. Rebecca Gilbert**, APDA Chief Scientific Officer, answers questions on **falls, preparing for specialist visits, and excessive sweating.**

**Q. I have had PD for about 10 years, and recently, I have been experiencing frequent falls. Why is this happening?**

**A.** Falls can be dangerous, and it's important to try to minimize them. There could be a number of reasons why you are experiencing frequent falls. Here are a few:

- Loss of postural reflexes, or the loss of the ability to right oneself when thrown off balance, is a very common part of PD.
- Drops in blood pressure is a common non-motor symptom of PD that can cause dizziness as well as passing out.
- Decreased visuospatial skills, which interferes with your ability to navigate your way around obstacles, can contribute to falls.
- Freezing of gait is an abnormal pattern of walking associated with PD in which there are sudden, short, and temporary episodes of an inability to move the feet forward despite the intention to walk. This can cause falls.
- Dyskinesias, or extra unwanted movements, can be a side effect of PD medication and can be throwing you off balance.

All in all, you need to discuss your falls with your neurologist who can investigate exactly what is causing your falls and try to correct it either with adjustments in medication, physical therapy, or an assistive device.

**Q. I was diagnosed with PD a few months ago by my primary care physician, and I have my first**

**appointment with a movement disorder specialist this week. Can you suggest ways to prepare for this visit?**

**A.** I would do three things to help make your visit the most productive and informative:

1. Bring along a “scribe” — a family member or friend who will take notes. Then you can review the notes afterward at your own pace.
2. Make a list of questions that you have and bring them along. Toward the beginning of the visit, mention to the doctor that you have this list, and you would like a few minutes at the end to discuss the things that have been on your mind.
3. Before the visit, make a list of any symptoms you have and how often you have them. It can be hard to remember everything at the appointment, especially if you're a little nervous. You can download the free APDA Symptom Tracker app to help you keep track of your symptoms.

**Q. No matter how much I exercise my legs, they don't get any stronger. They seem to just get weaker. What am I doing wrong?**

**A.** It can be frustrating when you hear about how important exercise is and how much good it can do you – but then you don't seem to be reaping the benefits. You may need to alter the frequency and/or types of exercise you are doing in order to build muscle strength. I would ask your neurologist for a referral to a

physical therapist. You can explain your issue to the physical therapist and he/she can come up with an exercise regimen that meets your needs and goals. Please note, Parkinson's disease should not cause actual weakness in your legs, but rather slowness and stiffness of movement. If your legs are truly weak, which your neurologist can assess, he/she may want to order other tests to rule out causes of weak legs.

**Q. I suffer from extreme hot periods with excessive sweating that typically occur in the evenings. Do you have any suggestions to help?**

**A.** Excessive sweating can be a non-motor symptom of PD. Moisture-wicking sheets, pajamas, clothing, and socks are available, which are made of materials that absorb more water and dry faster than standard fabrics. These can be very helpful for some people with excessive sweating. Remember to also stay hydrated, avoid sweat triggers such as spicy foods, and take cool or lukewarm showers. Be sure to let your doctor know if this is a new symptom for you as there can be other causes of excessive sweating that may need to be investigated.

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**Dr. Rebecca Gilbert** is the Chief Scientific Officer at APDA. She oversees APDA's research portfolio in conjunction with APDA's Scientific Advisory Board. She also provides medical and clinical expertise to support APDA programming as well as print and web content.

# Parkinson Symptom Tracking: The Value of Keeping Score

By **Laurie K. Mischley, ND PhD MPH**

If you're reading this article, you've probably been on a PD journey, your own or with a loved one. You've essentially been told, "We don't know how you got this, why you got it, when it started, how to stop it, or how fast it's progressing." I can only imagine the recipient of this [essentially useless] information feels disoriented, untethered, and adrift. Without reliable data points, how can we get oriented? How can we find our way if we don't know where we're starting from? How can we possibly chart a course without a map? One way to start creating your own personal map is through tracking.

## Tracking Medication & Symptoms



This morning a patient came in with the top of a yogurt container that she had turned into a clock, to remind her what time she

took her first dose of medication. While this works for the morning, things get confusing as the day progresses- I was thrilled to tell her there were easier ways to track her medication! Fortunately, [phone timers](#), [watch alarms](#), and the [APDA Symptom Tracker](#) are all useful ways to stay on top of medication doses

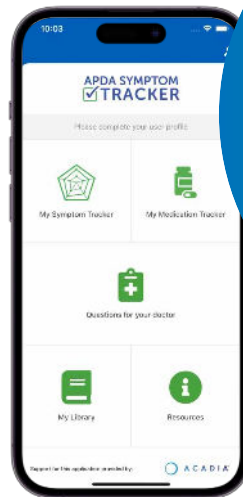
and ensure you don't fall behind.

While many people know their PD symptoms fluctuate over the course of the day, it is often difficult to offer more than anecdotal evidence. By tracking symptoms for several days, patterns can emerge and fluctuations can be reported to their provider. Once the provider understands which symptoms you're having *in relationship to the timing of your medications*, it becomes much easier to optimize dopamine delivery. There are paper templates available to describe fluctuating symptoms and the website, <https://www.parkinsonsmeasurement.org>, is an amazing resource to better

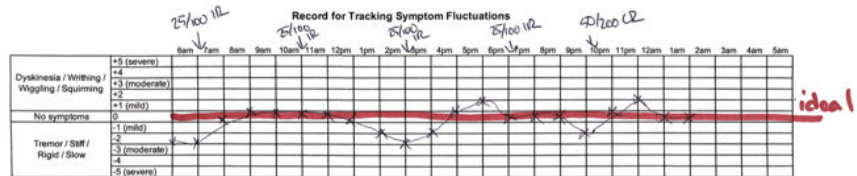
understand the delay between when you take your medicine and when your body receives it. Sometimes seeing how long a medication takes to kick in or how long it lasts can help optimize medications.

## Whose Disease is it Anyway?

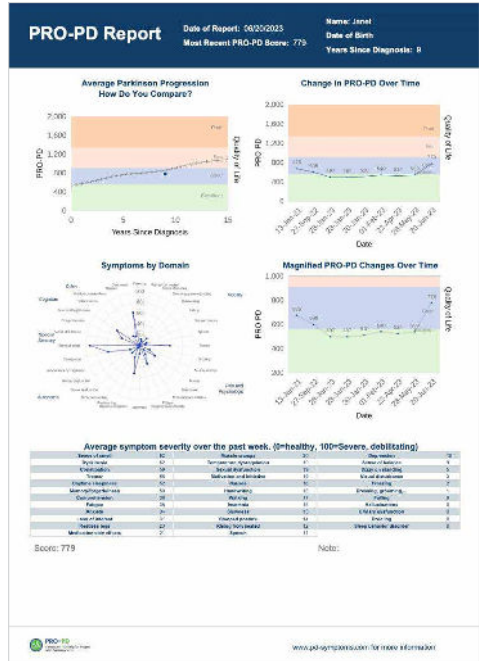
If you ask a pathologist to describe PD, they will talk about misfolded protein aggregating in dopaminergic neurons. If you ask a neurologist to describe PD, they will cite the cardinal symptoms: tremor, rigidity, stooped posture, and slowness. But when we ask patients to describe PD, the symptoms that top the list are fatigue, impaired handwriting,



The **Parkinson Symptom Tracking (PRO-PD) App** now is **freely available** on iOS and Android thanks to a generous donation by Don Johnson.



Percent of Patients Reporting Symptom	Symptoms
80-85%	Fatigue, Impaired Handwriting, Hyposmia
70-80%	Memory impairment, Muscle pain, Daytime sleepiness, Slowness, Tremor, Sexual impairment, Balance, Urinary dysfunction, Stooped posture
60-70%	Lack of motivation, Insomnia, Difficulty walking, Anxiety, Difficulty rising, Impaired speech
50-60%	Constipation, Difficulty dressing, Depression, Withdrawn, Acting out dreams, Comprehension, Restless legs, Drooling
40-50%	Dizzy on standing, Visual disturbance, Falls
30-40%	Dyskinesia, Freezing
<30%	Nausea, Hallucinations



loss of smell, cognitive impairment, and muscle pain. While scientists have been busy trying to stop protein aggregation, and clinicians are writing prescriptions to hide the motor symptoms, patients have not had an organized, structured way to tackle the symptoms of PD from the patient perspective. Patient-Reported Outcomes are an emerging set of tools that turn patient opinions into useful data.

(best) scores are socially connected, financially secure, exercising daily, and eating lots of fresh fruits and vegetables, nuts and seeds, fresh herbs & spices, seafood, olive & coconut oil, and beans! While on the flip side, lonely, sedentary people who eat meat, dairy, fried food, and soda have higher (worse) PRO-PD scores.<sup>3,4,5,6</sup>

### Tracking Symptoms and Progression

With highly fluctuating symptoms, many of which are difficult for a provider to observe, the PRO-PD tool was created to monitor symptoms from the patient perspective.<sup>1</sup> The scale has been shown to correlate well with existing measure of PD severity, but it can be done via the [Parkinson Symptom Tracking \(PRO-PD\) App](#) from home, without needing a clinic visit or a trained provider. Patients can generate a 1-page report that can be shared with their providers and used to monitor changes over time. In July 2023, a large Swedish study<sup>2</sup> concluded, “The PRO-PD was found reliable and valid for monitoring symptoms in a representative sample of outpatients with PD.” The validation of the PRO-PD opens new doors for research, patients, and providers and for the first time, enables users to observe trends and set goals.

PRO-PD scores do improve after starting dopamine or having deep brain stimulation surgery, and research has already been published demonstrating people with the lowest

### What Can the PRO-PD Report Do for You?

- Ensures Symptoms Don't Get Missed in Clinic - Too often motor symptoms are addressed when quality of life symptoms (poor sleep, anxiety, erectile dysfunction, fatigue, etc.) are ignored.
- Saves provider charting time - when a patient walks in with a completed report, the provider can spend time listening and learning, instead of typing.
- Enables goal setting - Making and tracking changes may encourage a patient to take steps in improving their quality of life.

Every day in clinic I see scores improve following lifestyle modification. And now for the million-dollar question: Can you make some changes - such as improving your diet, increasing exercise, and socializing more - that will improve (lower) your score and increase your quality of life? There's only one way to find out...

**Dr. Laurie Mischley** is a Naturopathic Physician, Parkinson Disease Specialist & Researcher. She practices at Seattle Integrative Medicine in Seattle, WA.

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To learn more about the app: [www.pd-symptoms.com](http://www.pd-symptoms.com)

To help us better understand how to change your score: [www.MVP-study.com](http://www.MVP-study.com)



# Managing Parkinson's in the Hospital: Strategies for Success

By **Nicole Hill**

Hospital stays throw a wrench into our routines. Everything gets turned upside down—medication schedules, sleep patterns, personal hygiene, bowel regimens, activities, and more. It's a mess for anyone, but for folks with Parkinson's disease (PD), it can be especially challenging and potentially risky.

PD isn't foreign to healthcare workers, but the level of knowledge varies greatly. They also won't be experts on your unique experience with the disease so it's important to communicate your needs during your stay. With a solid plan and a support system, you can prepare for any snags that come your way. What follows are some tips to help you get ready for your time in the hospital.

## Care partners and working with hospital staff

A care partner is crucial for emotional and physical support during a hospital stay. They can be a spouse, partner, adult child, family member, or friend you can rely on. While it's always good to advocate for yourself, don't discount the toll a hospital stay can take. You won't be at the top of your game, and a care partner is an invaluable advocate for you.

Developing a good relationship with the hospital care team is one of the best ways to lessen stress and complications. The care team is made up of doctors, nurses, aides, pharmacists, therapists, and nutritionists, all working towards your recovery.

**To build a trustworthy relationship with the care team and improve communication, consider the following approaches:**

- Introduce yourself in a friendly way.
- Inquire about visiting hours, overnight stays for guests, and care partner programs.
- Ask about the specific roles and limitations of a care partner.

- Compile a list of questions and concerns to address at once.
- Politely provide basic education about PD. APDA's "Parkinson's Disease Handbook" provides a terrific overview of PD and the "Aware in Care" Kit available from Parkinson's Foundation is another resource that can help educate hospital staff.
- Familiarize the team with your symptoms and your usual level of assistance.
- Inquire about the best time to contact the care team for updates and avoid calling during shift changes. Designate a point person to receive updates and relay information.
- Share personal details about yourself to establish a connection, such as hobbies, favorite foods, or pets waiting at home.

Educating the staff about the most relevant aspects of PD and how they impact you is helpful. It's valuable for the staff to know certain details of your daily routine, like when you typically feel your best, what foods help with nausea or constipation, how they can best assist with mobility, and information about your medication schedule.

The reality is, many hospitalizations are not planned and can't be prepared for as much as we would like. Identifying who will act as your advocate (care partner) and discussing these tips with them prior to an emergency can be of great help.

## Medications

Medications are a big deal when it comes to communicating with your care team. They might not fully realize how important your meds are and the impact they have on your symptoms so make sure you emphasize with them the need to stick to your medication schedule.

**Tips for handling your medications in the hospital:**

- Organize your medication list and ensure it is complete and accurate.
- Keep your medications in their original bottles, not in a pill box, and check the expiration date.
- Hand over your medications to the nurse for verification by the pharmacist.
- Timing can be a challenge due to pharmacy schedules, so educate the nurses about the importance of sticking to your medication schedule as closely as possible.
- Be aware that specific brands and dosages may not be readily available in the hospital pharmacy. If substitutes are suggested, inform the provider that it is usually not appropriate for PD patients unless absolutely necessary.
- Inquire about the option of taking your own medications during your hospital stay.
- If new medications are prescribed, ask about potential interactions with your PD medications and inquire about side effects, especially those related to movement or cognition.
- Be cautious with sedatives, narcotics, and anxiety medications, as they can increase the risk of falls or delirium.
- If the person with PD is not awake enough to swallow medications, then the carepartner should consult the person's neurologist to discuss options.

## Mobility

You can't talk about mobility without talking about falls, and your hospital care team hates falls as much as you do. The fact is the risk of falling increases when you're in the hospital. It doesn't matter why you're there—changes in medications, hospital equipment, and lack of sleep can all make mobility issues worse but there are ways to prevent falls and keep yourself safe:

- Follow the hospital's policies for fall risks. The staff knows what they're doing, so listen to their advice.
- Don't hesitate to use your call light when you need help. That's what it is there for!
- If possible, request a room with a bathroom nearby. It's so much more convenient and reduces the risk of accidents.
- Make sure you know who can assist you with getting up and moving around. Is



your care partner allowed? Clear communication is key.

- Be aware of any side effects that new medications may have, especially if they can cause dizziness or drowsiness.
- Be honest with your care team about your current level of activity. They need to know so they can provide the right support.
- Consider consultation with PT and/or OT. If it's not ordered, don't be shy—ask for it! Doctors often make decisions based on PT and OT recommendations.

### Mobility and Bedsores:

- Avoiding bedsores is crucial when confined to a bed or wheelchair.
- Turn every two hours to prevent bedsores; ask for assistance if needed.
- Nurses should assess skin integrity and provide padding for bony areas.
- Ask about using silicone dressings, gel pads, or heel protectors to prevent bedsores.

### Mobility and Hospital-Acquired Pneumonia:

- Reduced mobility increases the risk of fluid accumulation in the lungs.
- Take deep breaths multiple times an hour to prevent pneumonia.
- Try a breathing exercise to open up airways: Inhale deeply, hold, take an extra puff in, and then exhale.
- Practice this exercise both in the hospital and at home.

### Delirium

Hospital-acquired delirium is a temporary form of mental impairment that manifests as confusion, emotional disturbances, and behavioral changes. It results in longer hospital stays and worse outcomes and unfortunately, it often goes unrecognized and undiagnosed, being dismissed as “they're just confused.”

You'll have a much smoother recovery if you're able to avoid delirium. But if delirium does occur, there are some ways that your care partner can intervene to improve the situation:

- Let the daylight in: Open blinds and turn on lights during the day to provide stimulation and maintain a normal sleep-wake cycle.

- Create a peaceful environment at night: Talk to the staff about minimizing interruptions during nighttime hours to promote better sleep.
- Inquire about medications: Ask about potential side effects or interactions of any new medications, especially those that can affect mental clarity, such as narcotics or sedatives. Discuss the possibility of lower doses or discontinuation if appropriate.
- Stick to a routine: Establish a daily routine by noting important information like staff names and mealtimes. This can provide a sense of structure and familiarity.
- Monitor and communicate: Pay attention to any behavioral or personality changes and promptly report them to the medical staff. They need to be aware of any shifts in mental status.
- Bring a piece of home: Consider bringing familiar objects from home that can provide comfort and a sense of familiarity during your hospital stay.

### Other issues

Here are other common situations you might encounter:

- Pain control: Clearly communicate your preferred methods of pain management, whether it's medication, alternative therapies, or a combination of both. If your loved one is unable to communicate, inform the care team about signs to watch for indicating pain.
- Surgery: Medications are typically halted right before a procedure. Most meds can be taken with a sip of water, even when a patient is on NPO status (nothing by mouth). Ask about resuming regular meds as soon as it's safe. Watch for signs of delirium after surgery, as anesthesia can contribute to delirium.
- Dysphagia and aspiration risk: If you have difficulty swallowing (dysphagia), your risk of developing pneumonia increases. Inform your doctor if you're on a modified diet (e.g., soft foods, thickened liquids) and consider requesting a consultation with a speech therapist to assess your swallowing ability.
- Deep brain stimulator (DBS): If you have a DBS device, let the doctor and care team know, as they may not be familiar with it. Have the manufacturer's card

on hand so staff can contact them for information if needed. DBS may impact the type of imaging you can undergo.

- Duopa therapy: Similar to DBS, inform your care team about your Duopa therapy and be prepared to educate them about it. Have the manufacturer's information available for reference.
- Bowel issues and constipation: Try to maintain your usual bathroom routines as much as possible. Drink plenty of water, pay attention to nutrition, and keep track of bowel movements. If you experience difficulties, don't hesitate to inform the staff.

### Discharge

Just as preparation is an important factor in dealing with hospital admission, it's equally important for going home.

Ideally, a social worker, case worker, or discharge planner should have been in contact with you during your stay, assessing your home situation, coordinating with the care team, and planning for a successful discharge. If you haven't seen such a person by the second day of your stay, ask a staff member about it.

- Consider the following for your discharge plan:
- Will you need more help than usual? Short-term or long-term?
- Is rehab or a skilled nursing facility an option?
- Will you need additional resources or therapies?
- What follow-up is needed? How will you get there?

Support groups can also be incredibly helpful. Seek advice from those who have gone through similar experiences. They might have valuable insights about additional community resources. Or perhaps you just need a couple of meals brought in and a listening ear. Sometimes that kind of help can make a world of difference.

Navigating a hospital stay can be done. It takes preparation, communication, and advocacy. Do your best to be proactive, assert your needs, and reach out for support. If you can approach the process with a positive mindset, you make your pathway that much easier.

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**Nicole Hill** is a nurse and freelance writer.

# Beat the Freeze: Overcoming Freezing Episodes in Parkinson's

By Dr. Apurva Zawar, PT, DPT

## Introduction:

Freezing is a prevalent symptom of Parkinson's disease that affects an estimated 50-70% of patients at some point during the disease course. It manifests as a sudden and temporary inability to initiate movement or continue walking, posing a risk of falls and injuries.

Freezing episodes are often triggered by several factors, such as stress, fatigue, anxiety, medication wearing off, and complex environments. They can occur at any time of day but are most common during the morning when the medication effect is low and in narrow spaces, such as doorways, hallways, and elevators.

Freezing can be best described as a "short circuit episode" in which the brain has difficulty processing multiple stimuli. To manage freezing episodes, it is important to recognize, manage, and prevent freezing episodes using a range of strategies and tools.

Here's a quick guide to help you better manage freezing:

## Recognizing freezing episodes:

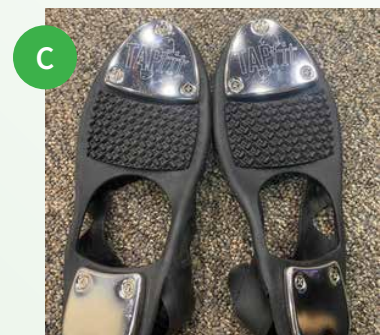
- The first step in managing freezing is to recognize when it occurs and what triggers it.
- Keep a diary or log of your freezing episodes, including the time, location, duration, and circumstances.
- You can also use wearable devices, such as the Apple smartwatch that helps in detecting mobility/steps and falls and provides feedback to the user and medical team.

## Figures:

A) Ball attached to a cane for visual cue

B) Laser light used as a visual cue, and

C) Tap shoes used as a sensory cue



## Managing freezing episodes:

Once you recognize freezing episodes, you can start using various techniques to manage them. Below are a few approaches to overcome the freezing episodes.

- **STOP - THINK - PLAN - DO:** This method involves pausing when you feel stuck, considering your next move, planning your actions, and executing them deliberately and confidently.
- **STEP STRATEGIES:** Utilize exaggerated alternating steps (right foot followed by left and so on) to initiate movement and maintain momentum.
- **BREATHING - ROCKING - CUEING:**
  - **Breath:** Practice deep breathing and stand upright while navigating new environments and tight spaces.
  - **Rocking:** Focus on rocking forward and back while standing, shifting your weight from side to side, and swinging your arms forward and back.

- **Cueing:** Use various cues such as:
  - Rhythmic auditory cues like counting, singing, or using metronome beats.
  - Visual cues like placing tape on the floor and stepping over it, attaching a small ball to a cane and gently kicking it to start moving, or using laser lights attached to a cane or walker to step over the light.
  - Sensory cues like attaching taps or [tap-fit shoes](#) to trigger movement through stimulus.

While using these cues, remember to focus on placing your heel first when initiating walking. If unable to move forward, try moving sideways first before attempting forward movement.

### Home safety modifications:

To create a more mobility-friendly and safe home environment, consider the following suggestions:

1. Craft a “guiding trail” by applying fluorescent tape or other luminescent materials on the floor. This enhances visibility in low-light or dark conditions, providing a safer pathway from the bed to the bathroom.
2. Try opening doors sideways for more stability.
3. Also keep clutter out of the way and use [assistive devices](#) as needed.

### Multimodal balance training

In addition to these techniques, it’s crucial to get a comprehensive assessment from a Neuro PT and appropriate recommendations to engage in home exercise balance training and/or community Parkinson-specific programs.

Multimodal balance training can include a combination of exercises, such as Tai Chi, PWR! Moves, boxing, yoga, or dance, which target various aspects of mobility and balance.

Managing Parkinson’s disease and freezing is an ongoing and evolving process that requires



Opening door sideways

“Repetitive practice in various environments and gradual progression with your balance training is the key to conquer your freezing.”

a multidisciplinary and collaborative approach. Therefore, it’s important to seek the right education and comprehensive training to improve your functional mobility, safety, and quality of life.

Everyone has their own unique characteristics and will respond differently to various prompts and strategies. To effectively manage and improve your level of functionality, it’s recommended that you regularly assess your progress, communicate effectively, and collaborate with your Movement Disorder Specialist & Neuro PT.

Repetitive practice in various environments and gradual progression with your balance training is the key to conquer your freezing.



**Apurva Zawar, PT, DPT** Dr. Apurva Zawar is an educator, mentor, and passionate neurologic physical therapist with expertise in treating movement disorders. She founded BeyondRehab, a digital Neuro-Rehab & Wellness clinic offering Telehealth services for individuals in California, Washington, New Jersey, and Massachusetts.

Her primary focus of work involves serving and managing movement disorder conditions

such as Parkinson’s Disease, Dystonia, Functional movement disorder, and Chronic Pain through integrative care & personalized evidence-based care that caters to each person’s unique needs and aspirations. In addition to her clinical work, Apurva is actively involved in research and serves as an APDA Northwest board member. You can learn more about her practice at [www.beyondrehab.health](http://www.beyondrehab.health)





An in-person event  
designed BY and FOR the  
**Young Onset  
Parkinson's Community**

**October 14th and 15th, 2023**

Four Point Sheraton Hotel, SeaTac, WA

*AGENDA*

**Saturday October 14, 2023**

Daytime: Social activity options include hiking, pickleball, boxing and more

Evening: Welcome happy hour reception

**Sunday October 15, 2023**

Full Day Conference 10:00 – 4:30pm

Featured Topics: Planning for the Future, Working & PD, Exercise Considerations, Treatment Timing, Nutrition and MORE!

**This two-day event is all about learning and making connections. The speakers, agenda and opportunities for social engagement are tailored to the unique needs of those living with Young Onset Parkinson's Disease, including the need for social engagement.**

*Featured Presenters:*

**Dr. Laurie Mischley**, Seattle Integrative Medicine

**Dr. Kimmy Su**, University of Washington

**Dr. Indira Subramanian**, UCLA Medical Center

**Dr. Nate Coomer**, The Parkinson Fitness Project

**Dr. Rebecca Gilbert**, APDA Chief Scientific Officer

*HOTEL INFORMATION*

**Four Point Sheraton Hotel >**

22406 Pacific Hwy S., Des Moines WA  
206-642-0100

Discounted Room Rates Available  
\$139/Night + taxes and fees (approx.  
\$160 total)

Limited quantity available, pricing  
returns to market rate on 9/15/2023



*Registration  
Information*

Registration Opens  
August 2023

*Regatta!* for APDA



Thank you and congratulations to our TOP FUNDRAISER Keith MacKenzie (center), skipper of At Last.

The 2nd Annual APDA Regatta on June 24 was a gorgeous day on the water hosted by Elliott Bay Marina. What was lacking in wind for the sailors was made up for with enthusiasm by the guests! The after-party crowd enjoyed live music, great food, and wonderful company, all while bidding on live auction items and fabulous raffle prizes.

**Thank you to our Regatta sponsors**

**ADMIRAL:** niagara BOTTLING, LLC

**CAPTAIN:** Aegis Living  
Associated Living | Memory Care

**SKIPPER:** Marina Management  
LFS



# The National Plan to End Parkinson's

By **Nicole Hill**

**On March 29, 2023, The National Plan to End Parkinson's Act was reintroduced to Congress. This bold national legislation will put into place a comprehensive and strategic plan to treat, prevent, and cure Parkinson's Disease (PD).**

**That's a lofty goal but a worthy one, and, more importantly, it's achievable.**

**Why does there need to be legislation surrounding PD? The short answer comes down to 2 words: Coordination and Funding**

## Coordination

One of the major pillars of the plan is to unify all organizations that touch on PD, federal and otherwise. The plan creates an Advisory Council with the responsibility to ensure the collaboration of efforts and activities among different agencies. The idea is that in coming together and harmonizing resources and research, priorities and recommendations will emerge faster and more efficiently.

The Advisory Council will be made up of members from federal agencies, non-profit groups, clinicians, researchers, and other experts. The Council will also include Parkinson's patients and caregivers. The American Parkinson Disease Association will work together with the Michael J. Fox Foundation (MJFF) and the Parkinson's Foundation, among others, as representatives.

The Council will meet quarterly to formulate and implement the National

plan and will be held accountable for achieving its goals. It will also be required to submit reports to Congress that provide an evaluation of federally funded research, programs, and clinical care with recommendations for improving health outcomes and quality of life. The reports will suggest actions to expand, prioritize or refocus efforts.

## Funding

Right now, the federal government investment in PD is around \$270 million. But the annual cost of PD in the U.S. is \$52 billion, and half of that bill is being picked up by the federal government. That big gap needs attention.

In its reports to Congress, the Advisory Council will propose the level of federal investment needed to prevent, treat, and cure PD. In other words, they'll suggest how much money is needed for real breakthroughs and progress to be made.

What about the other half of PD costs? The other \$26 billion? Patients and families have to foot that bill. The National plan also aims to address this burden.

The fact is, funding for PD has been stagnant for years. This bill would provide the groundwork to help grow future research funding to acceptable levels for a disease that impacts an estimated one million Americans.

It's important to note that while the bill addresses funding, the legislation itself is a no-cost plan. It simply brings together experts to look at how funding should be allocated and where it should come from. The goal is to reduce the financial impact on both the federal government and families.

## How YOU can help

The National Plan to End Parkinson's Act is bipartisan, which makes sense since PD doesn't care what your political affiliation is. The Act was first introduced in 2022, but Congress adjourned before it was up for a vote.

Once the bill passes into law, the real work begins. The federal government, along with all interested parties, will flesh out the details of the plan in an exciting joint effort to make real progress in treatment, early diagnosis, prevention, and even a cure.

APDA will be an eager participant in this process and will be turning to you, our constituents, for ideas and contributions as the National Plan is developed and put into action. Who better to advise us than those living with PD and their families and caregivers?

But there is something you can do now. In 2023 there is another chance for the act to become a reality, Add your voice to the cause by writing to your members of Congress and encouraging them to co-sponsor the bill. It's easy and fast. With just a few clicks and in a couple of minutes, you can join thousands of others to support and champion this life-changing legislature. Every voice matters!

Go to the website below to write to members of Congress. There are a couple options, including one with a pre-written message (super easy!). If you'd prefer to send your personalized story, that's great—it adds a degree of connection and the link below has suggestions on crafting your story.

**Together, we can turn the tide in the fight against PD.**

<https://michaeljfox.quorum.us/campaign/NationalPlanWriteNow/>





The Optimism Walk is part of a nationwide movement to mobilize and inspire people to step up and help put an end to Parkinson's disease.

## WE WANT YOU TO JOIN IN THE FUN!

Every year our APDA Northwest Optimism Walk is full of strength and hope. This year, we are excited to announce two distinct locations. The Seattle Optimism Walk is one of our biggest outreach events and largest fundraisers of the year. If you live south of Seattle, this year you can opt to join the Olympia Optimism Walk. Our combined goal for the Northwest Optimism Walks for 2023 is to register more than 750 walkers from all of our 5 states and raise \$200,000! Proceeds from the walks will keep people with Parkinson's connected, informed, and moving. And YOU can help!

**Register today as a Team Captain, Team Member, or Individual Walker.** Leading up to the walks, you will reach out to your network and ask for their support – every \$25 / \$50 / \$100 gift makes a HUGE IMPACT in paying for Parkinson's support programs, exercise and wellness classes, resources, education programs,

and research. As an Optimism Walk participant, you will help us celebrate our Parkinson's community as well as support APDA's mission to help everyone impacted by Parkinson's disease live life to the fullest. You will find that fundraising is FUN & EASY when it is for such a great cause!

Team Captains will receive a Rally Pack in the mail that will help you grow your team, provide motivation to fundraise, and generate excitement for the event. Together we can make an impact!

On **September 30**, join us in **Seattle** or **Olympia**, – or – walk in your own town and/or neighborhood!

### WIN PRIZES!

Fundraising incentives:

Raise **\$100** for an **Optimism Walk t-shirt**

Raise **\$500** for an **Optimism Walk hat**

Raise **\$1000** to **join Circle of Optimism** and **earn a medal** (and your name will be read during the Opening Ceremony!)

Prizes will be awarded for **Top Fundraising Team, Largest Team, and Most Spirited**





**THE  
DETAILS**

**APDA Northwest OPTIMISM WALKS  
Saturday, September 30, 2023**



**SEATTLE**  
Ship Canal Trail

**130 Nickerson Street**

Festivities begin at 9:30 am  
Opening Ceremony at 11:00 am

The Seattle Walk is an easy 1.5 miles down and back, you can turn around at any time.

**OLYMPIA**  
Marathon Park at Capitol Lake

**1011 Deschutes Parkway SW**

Festivities begin at 11:30 am  
Walk begins at 1:00 pm

The Olympia Walk is an easy 1.5 miles around beautiful Capitol Lake.

**SIGN UP TODAY!** [bit.ly/NW2023Walk](https://bit.ly/NW2023Walk)

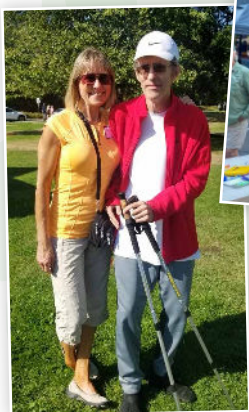
Walkers of all abilities are welcome. Bring the whole family!



**GET CREATIVE!**

**Best team name wins a prize!**

Creative team names from previous years:  
For Goodness Shake, Hike with Spike, Shake Rattle & Roll, Jan's Fans, Movers and Shakers, Dope-a-Team, Shaking not Stirred



**CAN'T GET TO SEATTLE OR OLYMPIA ON SEPT 30?  
ORGANIZE YOUR OWN COMMUNITY WALK!**

Recruit your family, friends, neighbors, support group and more and JOIN US on September 30 from where YOU live!

**PICK A LOCATION** for a short, non-competitive family-friendly walk, such as a park with a flat, accessible walking path. If your location is a public park with picnic tables and/or covered area, consider reserving for your event.

**PICK A TIME** You will want to allow 30 minutes for check-in, e.g. check-in at 9:30 and Walk begins at 10am.

**REGISTER A TEAM** at [bit.ly/NW2023Walk](https://bit.ly/NW2023Walk) Include the city/town name in your team name (e.g. Striders - Wenatchee).

**CONTACT APDA** with your Walk details and we will help by sending targeted emails and provide you with a flyer customized for your community Optimism Walk.

**GET THE WORD OUT!**

- From your team page you can easily invite others to join you
- Encourage Walkers to form their own friends/family teams! The more the merrier.
- Please include the city/town in their team name so APDA can clearly identify them and get any incentive prizes to you in time for your Walk!
- Let's STEP UP to help put an end to Parkinson's disease!



Strength in optimism. Hope in progress.

130 Nickerson Street, Suite 300  
Seattle, WA 98109

**SUBSCRIBE TO OUR  
NEWSLETTER!**

Sign up for our newsletter by visiting our website  
[apdaparkinson.org/Northwest](http://apdaparkinson.org/Northwest) or  
emailing [apdanw@apdaparkinson.org](mailto:apdanw@apdaparkinson.org)

**YES! I want to help provide the support, education, and research that will  
help everyone impacted by Parkinson's disease live life to the fullest.**

Please clip and return with your check in the envelope provided in the center of this magazine,  
or mail to us at **130 Nickerson St, Suite 300, Seattle WA 98109**

To donate by credit/debit card, please visit our website [apdaparkinson.org/northwest](http://apdaparkinson.org/northwest) or call **206.695.2905**

The Northwest Chapter of the American Parkinson Disease Association is a non-profit 501(c)3 organization. Our tax ID number is 13-1962771.



**ENCLOSED IS MY TAX-DEDUCTIBLE GIFT OF:** \_\_\_\_\_

My company \_\_\_\_\_ will match my gift. I will inform my employer that the  
American Parkinson Disease Association, Northwest Chapter, is the match recipient.

Contact me with information on how wills and bequest can support the Northwest Chapter of APDA.

Donor's name \_\_\_\_\_ Donor's email address \_\_\_\_\_ Phone \_\_\_\_\_

Donor's address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

This gift is given in honor of/in memory of \_\_\_\_\_ Please notify the above individual(s) of my gift

Honoree's address \_\_\_\_\_ City \_\_\_\_\_ State \_\_\_\_\_ Zip \_\_\_\_\_

***Thank you for  
your generosity!***