

WISCONSIN PARKINSON



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PREPARING & PLANNING:

Fall Prevention

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Please help us keep this magazine - and ALL WPA programs - 100% free for everyone who need them, by sending your generous gift today.

Thank you!

Letter from the NEW

Executive Director

I am so excited and honored to be joining the Wisconsin Parkinson Association as the new Executive Director. I look forward to bringing our team together with our many partners and constituents to carry out WPA's mission of providing hope, community, support, and resources for people with Parkinson's and their loved ones. I want to provide a brief personal background so you know a little more about me.

Professionally, I have spent the last 15+ years in human service roles in the nonprofit sector working with individuals of all walks of life, with the majority of that time spent at Goodwill Industries of Southeastern Wisconsin. My most recent role there was VP of Workforce Development, where I provided executive-level leadership, strategic development and execution of the organization's workforce development programs and services throughout Goodwill's service territory which covers southeastern Wisconsin and metropolitan Chicago.

I have a deep passion for mission-based organizations and realize the vital importance of connecting individuals with the services and support needed to live their best lives. My leadership style is very authentic and blends empathy with accountability and balances long-term strategy with short- to mid-term priorities. I have a BA in Psychology from UNC-Asheville where I played Division I Volleyball and an MBA from Alverno College in Milwaukee.

I live in the Greater Milwaukee Area with my husband Jon, a City of Milwaukee Firefighter, and our two amazing daughters Payton (13) and Blakely (10). We enjoy our family time exploring

the outdoors and traveling to National Parks.

I am drawn to the impact WPA provides to those directly impacted by Parkinson's Disease through educational resources, support groups and exercise/movement classes. Throughout my life and career, I've had many experiences, both directly and indirectly, where I've been personally touched by the impacts of a physical or mental diagnosis and understand the layers of challenges that weigh heavily through that journey for both the individual and their family.

I'm looking forward to leading WPA into the future, and am optimistic that, with a strong board of directors, our WPA team, and our many supporters and partners, we can grow and deepen our impact in the years to come.

As I begin my onboarding, listening and learning will be a key priority, and your input is valued. I'll be out in the field regularly visiting our various sites and regions. We have much work ahead together and I can't wait to meet all of you and get started.

Feel free to reach out anytime and connect. I'd love to hear from you.

Sincerely,
Kelly



Kelly Cieslak, Executive Director
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"The patient wasn't me, but rather my 20-year-old daughter, Samantha..."

Why Not Me?

The doctor said it was "Parkinsonian symptoms."

"As in Parkinson's?" I asked. I'll never forget his direct reply.

"I'm afraid so."

My mind began to spin a little as I tried to figure out what to ask next. I certainly wasn't prepared for this. It was hard to concentrate when you're suddenly told that a life-changing disease has shown up on your doorstep.

I've had migraines since I was a teenager, and I'd seen several neurologists over the years, but this was totally unexpected — especially since the patient wasn't me, but rather my 20-year-old daughter, Samantha.

Until that point, I had only a passing acquaintance with Parkinson's. Although I knew the actor Michael J. Fox was diagnosed with it in his late 20s, my picture of Parkinson's sufferers was of older people, particularly men, who had lived most of their lives before being afflicted.

But this was my baby girl, still in college, still trying to find her place in the world. This can't be happening, I thought. If anything, it should be me getting this diagnosis.

Multiple tests ensued, all of which confirmed the diagnosis. Samantha persevered, finishing her college education under a cloud of uncertainty. But for my wife and me, the diagnosis put us in the category of those parents we had often seen caring for a child with special needs. We wondered how they felt, how they coped, how they moved forward.

We wondered if we had missed the signs earlier on, or if our genetic makeup that we had passed on was responsible; if perhaps we had taken her to a doctor sooner, things might be different. Privately, I berated God for doing this. I made numerous Faustian deals with the devil to give me PD and spare my daughter.

Punt Parkinson's with the Pack

Soon after Samantha was diagnosed she decided she wanted to help others in the community. In 2013, she started Punt Parkinson's with the Pack.

To date the fundraiser has raised over \$77,000 for the WPA.



In 2021 alone, the event raised \$11,000.

Learn more online at
www.capturedbykaties.wixsite.com/puntparkwiththepack



You feel utterly helpless. You feel that somehow you failed your child by not keeping her safe. You feel like you shirked your parental responsibilities. You find doctors, you travel to find the best treatment (including three trips to the Mayo Clinic), you look for accommodations to help in whatever way you can. But eventually, reality kicks in and you move forward. You look at the best way to attack this unwelcome intrusion into your life.

Our family has adopted the philosophy that you can cry or you can laugh at your situation. We try to do more of the latter. That's not to say that there aren't still tears shed or the occasional epithet uttered about this cruel disease. But we try not to dwell on the negative and look at the positive side of life.

Positives? What positives can there be to having PD?

Well, I shamelessly play the Parkinson's card on my daughter's behalf. Looking for a donation for our Parkinson's fundraiser? I make sure they know why my daughter started it. Looking for meet-and-greet tickets for one of her favorite musical artists? I let them know that meeting them would (hopefully) put a smile on her face.

Parkinson's has taken me to the halls of Congress to lobby for more funding for all neurological diseases. I have met a number of incredibly caring people who will do whatever they can to help fight this disease.

But when all is said and done, a Parkinson's diagnosis sucks. But I would like to think it has made me a little more compassionate, a little more reluctant to be judgmental of others, and that it has increased my humanity and made me see the bigger picture of life.

...



(continued on page 7)

Keeping Balance & Preventing Falls

Why is fall prevention important for people with Parkinson's Disease?

If you have Parkinson's Disease (PD), did you know that you are at twice the risk of having a fall compared to your peers living without PD? Understanding why PD causes this higher risk for falls is important so you can learn how to prevent them and minimize injuries.

What causes this higher risk for falls?

The increased fall risk is associated with the motor and non-motor symptoms of the disease.

As PD progresses, balance is impacted by the changes in one's center of mass and base of support. These changes stem from the following:

- Postural changes (more "stooped" or "hunched" posture)
- Addition of an assistive device (walker or cane)
- Lower response time due to abnormal reflexes

- "Freezing" episodes
- Bradykinesia (slow movement)

Non-motor symptoms of PD can also increase your risk for falls. A few of those symptoms are:

- Low blood pressure
- Urinary incontinence
- Visual changes
- Fatigue and lack of sleep



Muddassir Mohiuddin, PT

Who can help? And how can they help?

Fall prevention requires multiple disciplinary approaches from primary care providers, neurologists, and rehab professionals such as physical and occupational therapists. It is always important to discuss your challenges with the correct medical professional so they can direct you in the appropriate direction!

Tips to be your best advocate:

- Make a list of what you're struggling with prior to your medical appointment so your provider can best address your needs.
- Take a caregiver or other supportive family member/friend who can help facilitate the conversation with your provider.



- Ask your primary care provider, neurologist and /or pharmacist to review your medications on a regular basis to see if any of them increase your risk of falling. *e.g. Your neurologist can help optimize your dosages and time of day you take certain medications so they don't exacerbate symptoms of PD.*
- Seeing an ophthalmologist can help you address any changing visual difficulties.

What about Physical and Occupational Therapy?

A physical therapist (PT) will help address motor symptoms by improving your posture, walking, and overall mobility. They can also help you establish a personalized exercise program targeting strength, flexibility, balance, and endurance – all designed based on your day-to-day challenges. Some of the non-motor symptoms such as blood pressure changes or chronic pain can also be managed by a physical therapist.

Occupational therapists (OT) focus on optimizing your activities of daily living (ADLs) such as housekeeping, cooking, and personal care. As PD progresses, these tasks can get more challenging. The risk of falls during self-care tasks like dressing and bathing heightens for someone living with PD. An occupational therapy evaluation is extremely beneficial because they can decrease your fall risk by customizing your home environment to meet your needs.

So What?

As you know, PD is a progressive disease that requires ongoing management; not only from your medical team, but also from your rehab professionals – physical, occupational and speech therapists. Ongoing care will maximize fall prevention knowledge, symptom management, and an overall enhanced quality of life.

(continued from page 5) **Why Not Me?**

...Over the last decade, Samantha has finished college with a teaching degree. She got a job teaching first graders for about a year until her disease forced her to quit teaching. She got married in 2018 and recently moved to Florida, because Wisconsin winters make her stiffness that much worse.

She's the same Samantha she was before Parkinson's: a little goofy, a little forgetful sometimes, if what she was supposed to remember isn't of great importance to her. Parkinson's may take little pieces

of you physically, but it can't take your soul.

I am optimistic, but also realistic in dealing with Sam's condition. It's not going to get better tomorrow, or next week, or next month. But I know that it's going to get better. I'm extremely optimistic that better days are on the horizon.

In the meantime, I find some comfort in the following words from Michael J. Fox: "When life takes away, something of greater value is always given in return."

“

When life takes away, something of greater value is always given in return.”

-Michael J. Fox



Christopher Potter, DPT

As I watch the sun dip below the horizon earlier and earlier in the afternoon this time of year, I am reminded that Wisconsin winters can last five months. This can be challenging as we seek the comfort of the warm indoors, comfort foods and increased time in bed. All of those things are wonderful parts of a change in season, but we know that motion is the potion for fighting Parkinson's disease.



So how do we stay active during the winter time?

If you are newly diagnosed with Parkinson's I recommend arming yourself with the tools that physical therapy, occupational therapy and speech therapy can offer you. Of course, I am partial to this plan, but I have seen patients objectively improve time and time again in my clinic when we apply evidence-based neuro re-education. This progress is compounded when my patient has an advocate such as a spouse or family member.

Winter is a great time to return to your therapist for a brush up. Consider them to be your primary care provider for how you are moving, speaking and processing. Establish functional goals with your therapist and you may find that a couple of sessions can get you back on a motivated track.

Establish a routine and write it down. This should correlate to your medication timing so that you are able to function optimally during times of activity. Wake up at the same time every day. Go to sleep at the same time every night. Sleep hygiene is critical to health and to reaping the benefits of exercise.

Joining a gym is a great idea. Many local gyms and YMCAs offer free or reduced memberships as part of Medicare's Silver Sneaker programs. Use the www.wiparkinson.org to find a suitable Parkinson's based movement class to check out. Keep track of your exercise at home or the gym by marking off a visible "X" or "O" in a bright color on your calendar. Strive to exercise three to five days per week as a goal.

Staying *Active* in the Winter

Ask a friend to meet you at the gym or for a walk to keep you accountable. Sometimes non-family members work better than a spouse.

Consider dosing your TV time. Reward yourself after activity with a positive program that brings you joy or provides education. Set a timer on your phone or the stove for an audible alarm to cue you to get moving every 30 to 60 minutes.

Get fresh air and sunlight every day you possibly can. Sunlight will help regulate your circadian rhythm. You will sleep better at night. Open the curtains, step outside or take a ride in the car. Visit a friend or a new place, make day trips to new destinations or old favorites to stimulate your brain and get your body up and out the door.

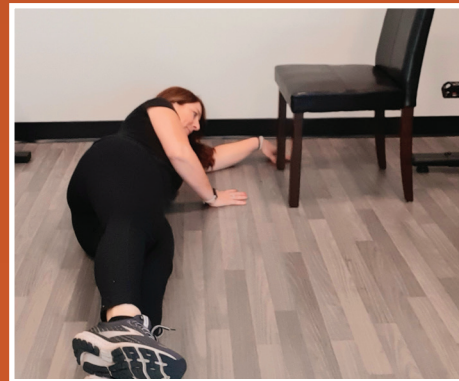
We are blessed with the beauty of the changing seasons in Wisconsin. Observe the changes outside with wonder and reflect on the things you are grateful for in life.



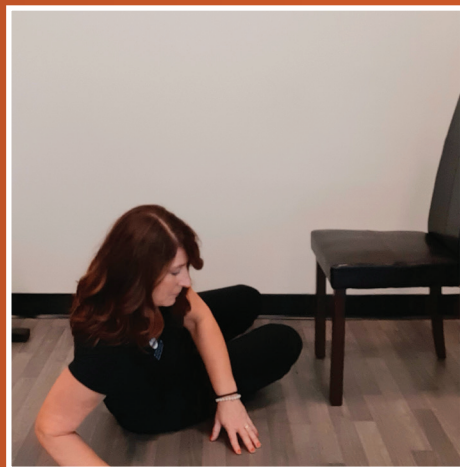
At-Home Exercises

Follow these simple steps to safely get back up after a fall and prevent further injury. To practice these step, follow them in reverse to get down to the floor first, then follow in order to get back up.

Exercises provided by Mary Wood, WPA's exercise coordinator.
Find her exercise class in your area or virtually at wiparkinson.org.



1. First, assess yourself for injury. If you are uninjured, start by rolling onto your side.



2. Bend the leg that is on top and push yourself onto your elbows or hands.

3. Push yourself into a sitting position or crawl to the closest chair or object.



4. Kneel in front of the chair or object, place both hands on the chair or object. (Optional: kneel on pillow or towel)



5. Place your stronger leg in front, holding on to the chair or object.

6. Push up using your leg strength and upper body to stand up.



7. Very carefully, turn and sit down, rest before trying to move.

Welcome to the WPA Corner!

We intend to use this space to keep you updated on the programs and services provided by WPA and make sure you can utilize all of the resources we provide.

The reason we started this is to share what our program's mission has been, what we were able to accomplish over the past 18 months, and where we are going in the future.

Over the past 35 years, WPA has focused on educational programs and support groups. This has evolved as the number of in-person programs has grown and support groups expanded to include exercise groups. Prior to 2020, we provided eight in-person programs and supported over 210 support and exercise groups. All of these offerings were in-person, which meant that if you could not leave your home or did not have transportation, you were unable to participate in these offerings.

Then COVID happened. We had to stop all in-person meetings and programs. Originally, we expected this to be for two or three weeks, which then extended into much longer. During this time, WPA grew and adapted. We moved to online programs and group meetings. We found that by holding virtual programs we reached people from all over Wisconsin and other states. Additionally, Mary Wood, Exercise Coordinator with WPA, started a Facebook Live Music & Movement class which drew nearly 600 attendees, one as far away as New Zealand. During this time, we increased the number of videos on our website from three to over 200! These videos cover a variety of topics directly related to PD, but also include Home Health Care, Will and Estate Planning, and Driving questions. The good news was that we now were reaching people who couldn't attend in-person

WPA Corner

programs in the past. No matter where you lived in Wisconsin, you could see and hear speakers from anywhere in the state. The bad news was that we missed a number of people who were not comfortable using computers for programs.

With learning our virtual capabilities and knowing our in-person efforts, we have a plan to continue to grow and improve our programs. Starting with the Symposium in July, future programs will be offered both in-person and online. We will live stream our programs, but also record them for future reference. We do ask for your patience, as there will be a learning curve to our streaming programs in the beginning. We need to perfect the video and audio but hope the growing pains will be worth the opportunity to attend programs on the other side of the state without leaving home. Our first attempt, the Symposium in July, was promising, with 225 people attending in-person, plus another 100 from their homes.

We hope you are looking forward to these future opportunities and growth of our programs. With these developments, instead of attending one or two in-person programs a year, you will now be able to attend as many as you want.

Next issue, we will discuss our support and exercise groups and the transition of meeting in person going forward.

Would you like to receive Wisconsin Parkinson Magazine?

If you do not receive *Wisconsin Parkinson Magazine* quarterly, join our mailing list at wiparkinson.org. You will receive this magazine, as well as periodic information about educational events, support & exercise groups, and other resources in your area. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to you and your families. For more information, visit wiparkinson.org.

Wisconsin Parkinson Association provides hope, community, support, and resources for people with Parkinson's and their loves ones.



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