

“You are not alone.”



Parkinson Partners’ Mission Statement: To encourage, educate and support those with Parkinson’s disease, their caregivers and loved ones as they cope with the challenges of disease. Exploring better resources, services and outcomes for people with PD.

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Please remember Parkinson Partners in your estate planning. Your gift can ensure that local services and support continue for the Erie PD community.

10 Things Women with PD Can Do to Get the Care They Need

By Brian P. Dunleavy--Medically Reviewed by Jason Paul Chua, MD, PhD; March 4, 2022

If you didn't know that women can get Parkinson's disease (PD), you might not guess it from the images of Parkinson's you'll find online, most of which depict older white men. Although according to the Parkinson's Foundation it's true that men are nearly twice as likely to be diagnosed with PD as women in some parts of the world, that doesn't mean that women don't develop the disorder. They do.

Studies suggest it takes longer for women with PD to get a proper diagnosis, due at least in part to the perception that they're far less likely to develop it, according to Indu Subramanian, MD, a neurologist who specializes in movement disorders at Ronald Reagan UCLA Medical Center and the West Los Angeles Veterans Administration.

“Parkinson's does tend to be male-dominant, but it's still an equal-opportunity disease,” says Dr. Subramanian, who recently coauthored a review article on care “gaps” seen in women with Parkinson's. “It can strike someone of any gender and any race, and younger people can develop it as well. However, people who don't fit into that stereotypical label of the Parkinson's patient may need to make an extra effort to ensure they get the care they need.”

“Two of the most prominent faces of PD are men — Michael J. Fox and Muhammad Ali,” says Ryan P. Duncan, DPT, an associate professor of physical therapy and neurology at Washington University in St. Louis who treats people with Parkinson's disease and other neurological conditions. “Given this public perception, which likely affects medical providers, it's easier to understand why women exhibiting signs consistent with PD might be dismissed or misdiagnosed,” Dr. Duncan says.

So what can women with Parkinson's do to make sure their care needs are met? Here are a few important steps.

1. Be Aware That Even Young Women Can Have Parkinson's Disease: Self-education is vital for anyone with PD, but particularly for young women, because a lot of the healthcare professionals they see may not be fully aware of the disorder can strike this demographic, Subramanian says. She advises women to learn how PD tends to affect women, including potentially unique symptoms and symptom progression. “You may need to be extra-attentive and monitor your own symptoms,” she says. “Being able to spot symptoms early, as they develop, can help you be more proactive about care.” Be sure to get informed, using vetted, credible resources such as the Parkinson's Foundation, Michael J. Fox Foundation, PMD Alliance, and the Davis Phinney Foundation for Parkinson's.

2. Find Healthcare Professionals Who Understand You and Your Care Needs: It's unfair for women with Parkinson's to “carry the weight” of their own care, Subramanian says. That's why it's vital that they work with a care team — including neurologists and physical and occupational therapists — who understand their needs and make them “feel seen and heard,” she adds. Do some research about potential providers before you begin working with them. See if their practice or clinic emphasizes diversity and inclusion. During your initial visits, look around the reception area. If you see a diverse group of people, that's a good sign, Subramanian says. If you feel comfortable doing so, ask other patients what they think of their providers, she advises.

3. Understand That PD Affects Different People Differently: There are common symptoms of PD — such as tremor — but that doesn't mean that everyone with Parkinson's experiences them. Though tremor is common in women, “at least 10 percent of our patients don't have it,” Subramanian says.

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News and Notes

Meeting Cancellation

Policy: Meeting changes and cancellations due to weather or unforeseen circumstances will be posted on our Facebook page. You are also welcome to call or text our office number 814-899-3030 for up-to-date meeting information.

Save the Date: Parkinson Partners and Encompass Health Rehabilitation Hospital will be hosting a lunch and learn with a wellness theme on Thursday, April 20th. Details are still being decided but watch your newsletter and emails for more information.

Save the Date: "PD: The Basics and Beyond" webinar will be held on Friday, April 21st. Our keynote speaker will be UPMC Hamot Movement Disorder Neurologist Dimitrios Nacopoulos, MD. Watch the newsletter and emails for registration information.

What Topics Are You Interested In? I am working on scheduling more speakers for upcoming meetings and events. Please let me know what subjects you would like to learn more about.

Mark Your Calendars:

Lake Erie Speedway will be hosting Great Lakes Cars and Coffee, a car show in tribute to Elmer "Porky" Chambers on Sunday, July 9th from 8:00 AM-noon. 50% of the gate proceeds will be split between Parkinson Partners and the Alzheimer's Association. For more information go to: <https://www.lakeerispeedway.com/great-lakes-cars-coffee>
We are so grateful to have been selected as one of the chosen charities and hope many of you will come out and support this great event!

Home PD Exercise Options Including Local Options

Here are some at-home exercise options. The links are LIVE so if you are reading this newsletter online, just right click on the link and you'll be taken directly to the website. Remember to consult your physician before starting any new exercise program.

Local: Our Purposeful Movement and Wellness team including Gannon University Professors Dr. David LeVan, OT and Dr. Courtney Roca, PT and retired Professor Tom Hudson, PT along with graduate OT students Taylor Mandley, Lily Bargabus, Ashley Tomasko and Brianna Murosky, Aurora Brown, Lauren Greenlee, Caitlin McKee, Carrie Pratt, Claire D'Amore, Alexandra Gyory, DPT student Brandi Tirado and Radiological Sciences student Riley Fanaro, have created some home exercise videos that you can access on YouTube:

- **NEW:** <https://youtu.be/DKXrGoaizJ8>
- **NEW:** <https://youtu.be/C7Y8rLMUjzA>
- Winter 2021: <https://youtu.be/HqUZ7CyOcjA>
- Winter 2021: <https://youtu.be/shnsCH9rqC8>
- Fall 2020: <https://youtu.be/mowyEAf7qK0>
- Fall 2020: https://youtu.be/PZ62_U84Hq8
- Fall 2020: <https://youtu.be/fFkGBU-vJ90>
- Summer 2020 Part 1: <https://youtu.be/lcsBTPoX1dU>
- Summer 2020 Part 2: <https://youtu.be/l8pjbERaxA>
- Spring 2020 Part 1: <https://youtu.be/-ud1erTZcmA>
- Spring 2020 Part 2: <https://youtu.be/2XiSyoixBfM>

Seated:

- Power for PD: <https://www.youtube.com/channel/UC9QTeS9SMZKbSzDS-nvhr3g/videos>
- Sit and Be Fit: <https://www.youtube.com/user/SitandBeFitTVSHOW/videos>

Seated and Standing:

- Unique Physique Fitness Center: <https://www.facebook.com/watch/UniquePhysiqueFitnessCenter/>
- APDA: <https://www.apdaparkinson.org/free-online-exercise-and-therapy/?eType=EmailBlastContent&Id=4c51adf3-809e-4c84-b67a-623c6512cf34>

LIVE Classes from Parkinson Foundation of Western PA: remember you must pre-register to attend these live classes. There is a large variety of options so we encourage you to check them out. Thank you, PFWPA for including our group.

Best Wishes for those with Special Celebrations

Happy Birthday and Happy Anniversary to our members!

To have your birthday or anniversary added to our list call 814-899-3030 or email: info@ParkinsonPartners.org

March

2—Dave Barron
4—Mike DiNunzio
5—Dave LeVan
20—Carolyn Bard
23—Phil & Denise Wahler Anniv.
25—Chuck Leone
31—Lynne Gotham

April

2--Dave Brown
7 – Denise Wahler
10 – Audree Parr
19—Paul Jewell
28--Nancy Brown

Women and PD continued from Page 1: Research suggests that women are more likely to experience mental health symptoms related to PD, such as depression, anxiety, and disrupted sleep “years before they develop subtle motor symptoms,” she adds. Motor symptoms are those that affect physical movement. Other important symptoms for women to know about include bladder and pelvic floor issues, constipation, and sexual dysfunction. “Women with Parkinson’s disease report more genitourinary problems compared with men,” Duncan says. “If women with PD are having these issues, it’s important they raise this with their provider, because there are physical therapists specially trained to address these issues, and working with these professionals could lead to a substantial improvement in quality of life.” Women also experience more pain with PD than men. Too often, though, these symptoms are overlooked or dismissed, particularly by healthcare professionals who are too focused on motor complications, Subramanian notes. Learn about all PD symptoms and, if you notice anything new or different, tell your care team.

4. Don’t Be Stoic: In Subramanian’s experience, women tend to downplay or suffer in silence with their PD symptoms. Advocate for yourself, and if you feel that something’s wrong, do something about it. If you feel a care provider isn’t listening to you, work until you find one who does, she recommends. “Take care of yourself — you’re very important and no less important than anyone else in your life,” Subramanian emphasizes. “It’s hard for women to take the time they need to give themselves love and nourishment. You need to take care of yourself before you take care of anyone else in your life.” Duncan adds, “Don’t be afraid to share your experience. Parkinson’s disease affects much more than movement. It can also affect mood, energy level, thinking, self-esteem, and interest in doing things you previously enjoyed. The more women share with their neurologist, physical therapist, and other care team members, the more the team can help.”

5. Track Your Symptoms Around Your Menstrual Cycle: In premenopausal women, menstrual cycles may influence PD symptoms, according to Subramanian. “The hormonal cycle can affect your symptoms quite dramatically,” Subramanian says. “Some women report worsening PD symptoms around the week before their menses or as they go into menopause.” Women who are pregnant may also notice changes in their symptoms. If you’re planning to have children, talk to your care team about steps to take to help you through your pregnancy and delivery, Subramanian advises. This may include extra sessions with physical therapists and occupational therapists designed to help you identify strategies for maintaining mobility and doing the things you need to do while pregnant and caring for a newborn, she says. Ideally, you should pursue this extra care before getting pregnant so you’re ready when the time comes, she adds.

6. Ask for a Specialist Referral: Studies have shown that it takes up to 60 percent longer for women to get a Parkinson’s diagnosis and get referred to a neurologist who specializes in movement disorders once they get diagnosed. “You should be evaluated by a specialist at least once a year if you have Parkinson’s,” Subramanian says. “If you’re not getting a referral, find a provider who will make sure you get the care you need.” Along these lines, your care team may include other providers in addition to your neurologist, such as a physical therapist, an occupational therapist, yoga teachers, personal trainers, dietitians, psychologists, social workers, and even spiritual leaders, both she and Duncan say.

7. Get Organized Before Doctor Visits: Preparing for your doctor appointments is crucial for anyone with a chronic condition, but particularly so for those whose symptoms and experiences risk being dismissed or ignored. Here are some ways to make sure you remember all the things you want to discuss or ask your doctor about during your visit.

- Document your symptoms in a diary or journal and bring it with you.
- Make a list of questions for your provider before appointments.
- Bring a list of the medications you take, and their doses, with you, or bring the pill bottles themselves.
- Most important, bring someone with you, a friend or relative, perhaps, or someone you know who also has PD. “Who is your biggest cheerleader in your life? It may be your sister or your best friend,” Subramanian notes. “Bring them to your appointments and include them in how you are feeling. Ask them to help you document your symptoms so you can communicate with your providers.”

8. Get Support From Family, Friends, and Groups: Support from friends and family is vital for anyone dealing with a major health problem. For women with PD, who may experience the emotional and mental effects of the disorder more acutely, it’s essential. Even if your spouse is supportive, there may be symptoms you don’t feel comfortable sharing with them, Subramanian notes. So, getting support from “outside the home” is important, she advises. In addition, there are many support groups worldwide for women with PD, including several that meet online. Subramanian’s favorites include Twitchy Woman, which offers peer-to-peer mentoring and, for Spanish-speaking women, Con P de Parkinson. “You will do better if you have a tribe: Social connection in Parkinson’s disease is huge,” Subramanian notes. “Having a group of friends who you can feel connected to outside your home is important. Planning social activities with these people is important. Laughing, playing, relaxing, and sharing your stories with others is tremendously beneficial.”

9. Work on Daily Wellness: Wellness and overall health is important. Subramanian recommends finding proactive things you can do for yourself every day that make you feel better. Think about incorporating exercise and mind-body strategies such as yoga or mindfulness. “What do you like to do? What brings you joy and meaning?” she says. “Find ways to increase these in your life. Realize that sleep, hydration, and a healthy diet can make you feel better.”

10. Get Involved in Advocacy: If you can, get involved in PD-related advocacy. Subramanian suggests reading the book *Ending Parkinson’s Disease* and joining the PD Avengers as a good place to start. Participation in clinical trials can be very empowering and give women living with PD a tremendous sense of purpose, she says. To date, most clinical trials for drugs and devices for PD have focused on white, affluent, older males, and that has impacted treatment, she adds. Women need to come forward and be heard and actively participate in advocacy and research if they want future care to reflect their unique needs.

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DONATIONS:
Checks should be made payable to "Parkinson Partners" and mailed to the address above. Donations can also be made via PayPal on our website.



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We're on the Web!

See us at:
www.ParkinsonPartners.org

DISCLAIMER: The material presented in this issue is solely for the information of the reader. It is not intended for treatment purposes, but rather as a basis for discussion with the patient's physician.

Support Group Meeting Schedules

Remember: all events are also listed on our Events Calendar on our website including live links to Zoom meetings.

ZOOM MEETINGS:

- **Parkinson Partners Support Group Meeting** via Zoom on **Wednesdays, March 8th and April 5th and 19th (NO meeting 3/22) at 1:00 PM.** Join Zoom Meeting: <https://zoom.us/j/93010770942?pwd=bzhTYTgxVElXV0pONnYwbEt5TnZzZz09>
- **Parkinson Caregiver Only Support Group Meeting** via Zoom on **Thursday, March 23rd and April 27th at 1:30 PM.** Join Zoom Meeting: <https://zoom.us/j/96391675305?pwd=ZHqxbXhnRS9GTGpKdlpTeURHSiJJdz09>

IN-PERSON MEETINGS:

- **Wegman's PD Support Group** will meet at the Peach Street Wegman's on **March 14th and April 11th at 5:30 PM for newer members with the rest of the group joining at 6:00 PM** in the dining area. All are welcome.
- **Care Partner Only Lunch:** Join other Care Partners for conversation at Peach Street Wegman's on **Monday, March 27th and April 24th at 11:30 AM.**