

**“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.

Intimacy Can Be Challenging with Parkinson's Disease

By Sherri Woodbridge: February 6, 2019 at <https://parkinsonsnewstoday.com/2019/02/06/intimacy-challengin-parkinsons-disease-tips-communication/>

The other day, my husband told me he felt alone. Then he said he felt distanced. How could that be? We are together almost every day, 24/7. But being together and *being together* are very different, especially when it comes to having Parkinson's disease.

This disease has many symptoms, of which tremor is the most prominent. Other symptoms are not often discussed, particularly depression. Another that I will discuss in this column is intimacy difficulty.

Most people with Parkinson's are aware that intimacy can be an issue for many reasons. One may be an unintentional lack of interest the person with PD may not even be aware of. Another may be pain or discomfort. Yet another may be the inability to "perform." Any of these reasons can disrupt the relationship, sending messages of rejection or appearing to indicate the partner is undesirable and even unloved.

First, let me say that, whether you're the person with PD or the partner, you are not alone. I, too, struggle with this subject for many reasons. I can feel inadequate in many ways, but I didn't realize I was inadvertently making my husband feel distanced and alone until the other day when we had a heart-to-heart talk.

According to the American Parkinson Disease Foundation, "From lack of sexual desire to low libido to difficulties with orgasmic functioning, this chronic, progressive, neurological disease can impair your sexuality in one way or the other." The Michael J. Fox Foundation adds that "as many as 70 to 80 percent of those with PD experience sexual dysfunction."

Dealing with bradykinesia, or slowness of movement, and rigidity can become an issue in a relationship. Symptoms such as tremors and dyskinesia also can contribute to dysfunction and leave one or both partners feeling inadequate. This also plays out in everyday signs of affection such as hugging, kissing, or holding hands. The person with Parkinson's can appear aloof to the need for affection and leave a partner feeling more distanced with each day. Before long, both are wondering why the other has stopped finding them attractive and don't want to be with them sexually anymore. I can't help but believe that the sad stories I have heard about spouses who have left their partners with Parkinson's disease are more likely due to a lack of communication than just having the disease.

It's hard to overcome feelings of inadequacy when they are kept bottled up and aren't talked about. The first person to talk to about how you're feeling is your partner or spouse. A frank and honest discussion about the effects of Parkinson's on intimacy and how to overcome it in everyday life is critical. It might mean an intentional hug in the morning or time set aside only for conversation. (This does not include talking while watching the television.)

Speaking of television, the other day, I was watching a show and at the end, a man proposed to his girlfriend. Of course, she said yes — it was a Hallmark movie, after all. Then the guy said, "I hope the magic never fades."

None of us wants the magic to fade, especially if we have Parkinson's. It's taken so much already. We need to keep communicating with each other, no matter how hard it may be at times. It's those times that bind us together more tightly, and the tighter we hold each other, the greater the magic will be!

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.

🎵 Are you on Facebook? Parkinson Partners has a very active Facebook page that will keep you updated on the latest local and national PD news and tips for those with PD and their family. The next time you are on Facebook, check us out and "LIKE" us.

🎵 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.

🎵 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!

MAY YOU FIND THE
STRENGTH
TO FACE TOMORROW
IN THE LOVE THAT
SURROUNDS YOU TODAY

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/l8pjybERaxA>
- 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



Local Resources: Did You Know These Are Here for You?

- **Speech and Language Services:** PennWest University-Edinboro is home to the Governor George Leader Speech & Hearing Center where we offer speech and language therapy services for both children and adult. As part of our clinic, we offer the Parkinson's Voice Project's SPEAK OUT!® and LOUD Crowd® Programs. The mission of this program is to help individuals with Parkinson's and related movement disorders to regain and maintain their speaking abilities. As Parkinson's is a progressive, degenerative condition, those with Parkinson's Disease oftentimes find the muscles involved in both speaking and swallowing can become weak. During our speech sessions, we encourage our members to not only speak with intent but live with intent in their daily lives. The SPEAK OUT!® program consists of individual therapy sessions followed by membership in the LOUD Crowd®- a group maintenance program. The key components that make up the LOUD Crowd® program are daily vocal exercise, the conscious use of INTENT, ongoing instruction from a speech language pathologist, and support and encouragement from care partners and peers. If you or someone you know would be interested in this therapy program at no cost – please contact the Governor George Leader Speech & Hearing Center at (814)-732-2433 or email atleaderenter-edn@pennwest.edu. You can also contact Chris Shumaker, Clinical Instructor, at PennWest for additional information at cshumaker@pennwest.edu.
- **Memory Café**--1st & 3rd Thursday of each month – 1 to 3 p.m. (closed for summer in August) Caring for a person with Alzheimer's disease or dementia of any kind, can take its toll physically, emotionally and financially. Opportunities for all involved to enjoy the company of others in a relaxed and friendly atmosphere are few. A Memory Café provides just such an opportunity, and Erie now has such a place. The Unitarian Universalist Congregation of Erie hosts a Memory Café on the first and third Thursday of each month from 1 to 3 p.m. The church is located at 7180 Perry Highway in Erie, just one mile north of the I-90 & State St. interchange. Attendance is free and open to the public. With dementia, caregivers and the afflicted have little opportunity to experience each other socially. At the Memory Café, participants can socialize, learn and share their experiences with others in similar circumstances in a stigma-free environment. More than 5 million Americans are living with dementia, and support is greatly needed in our community. The friendships and joy that resonate from these cafés bring light and life to both people with dementia and their caregivers. Reservations are preferred but not necessary and can be made by calling 814-864-9300.
- **The Sandra Mead Memorial Transportation Grant**, administered though Parkinson Partners, will provide a \$50 gift certificate for Hansen's Errand Service in Erie to be used for transportation or errand services. To be eligible, the applicant must have a diagnosis of Parkinson's disease or Parkinsonism and reside in Erie County. After receiving your application and determining your eligibility, you will be notified of your approval and a gift certificate will be issued to you. You will receive a follow up survey to determine the benefit of the program. This is a pilot program and may be continued in the future provided there are necessary funds and that there is still a need in the community. Applications are available on our website: <https://www.parkinsonpartners.org/home-2/programs/>
- **Presbyterian Senior Care Network Adult Day Program** is life-enhancing to your loved one with dementia—and to you! You might already know firsthand: Alzheimer's disease is life-changing for the person with the diagnosis—and for the people who love them. So, having a helping hand when you need it is key to reducing stress and feeling well-balanced. At *Woodside Place* at [Manchester Commons](#) in Erie, PA, adult day care support is ready to help. Call 814-838-9191 for more information.
 - **What is adult day care?** It's a special program for people living with Alzheimer's or other dementias that gives them opportunities to socialize and participate in activities in a safe environment.
 - The full- or half-day adult day program at Manchester Commons could be just the support you both need if:
 - **You are a full-time caregiver:** Adult day care can give you a much-needed break: While your loved one is at Woodside Place, you'll have time to rest, run errands or finish other tasks.
 - **You work during the day:** Adult day care at Woodside Place can help you balance a job with caregiving duties.
 - **You want a safe, caring environment for your loved one:** Adult day care at Woodside Place is the chance for your loved one to share time with peers and engage in activities, such as music, exercise, and safe, supervised outings.

Parkinson Partners of NW PA, Inc.

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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.



Parkinson Partners of NW PA, Inc.
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If you wish to be removed from the mailing list, please call 814-899-3030.

Like us on Facebook!



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, February 22nd and March 8th (NO meeting 3/22) at 1:00 PM.** Join Zoom Meeting: <https://zoom.us/j/93010770942?pwd=bzhTYTgxVEIXV0pONnYwbEt5TnZzZz09>
- **Parkinson Caregiver Only Support Group Meeting** via Zoom on **Thursday, February 23rd and March 23rd 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 **Tuesdays, February 21st and March 14th 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, February 27th and March 27th at 11:30 AM.**