COLUMBIA | NEUROLOGY

LIVING WELL WITH PARKINSON'S DISEASE

Spring 2024

7 Things Every Person with Parkinson's Should Know

If you or your loved one has recently been diagnosed with Parkinson's disease (PD), it is normal to feel overwhelmed. Below we highlight seven things every newly diagnosed person should know, featuring information from the **Parkinson's Foundation's Newly Diagnosed guide**.

1. **You are not alone.**
There are one million people living with PD in the U.S. and nearly 90,000 are newly diagnosed every year. Even if you have a relative or friend with PD, a diagnosis may feel shocking. Know that there is a passionate PD community ready to support you, in-person and online. When you're ready, the Parkinson's Foundation has information and resources that you need. Call their helpline at 1-800-4PD-INFO (1-800-473-4636).

2. **Adjusting to a diagnosis takes time.**
It's common to experience a wide range of emotions after receiving a diagnosis — relief, sadness, confusion, and determination, to name a few. Take the time you need to understand what you're feeling and reflect on what brings you joy. Begin to educate yourself on PD and the steps that you can take to live well. Taking control of the things you can, like staying informed, will help to minimize stress.

3. **Parkinson's symptoms affect more than movement.**
Though PD is often thought of as a disease that only impacts movement, most people develop other symptoms as well. Early signs of Parkinson's include tremor, small handwriting, loss of smell, trouble moving and trouble sleeping. Many people with PD experience non-movement symptoms related to mental health like depression, anxiety and apathy. If you are affected by these symptoms, know that you are not alone. Prioritizing mental health is critical to overall well-being. Consider reaching out to a loved one, a counselor or a spiritual advisor and start building your support team.

4. **Every person's experience with PD is unique.**
As you start to learn more about this disease, remember that everyone's journey is different. No two people with PD will have the exact same symptoms or rate of progression. Begin tracking your symptoms to develop a stronger awareness of how PD impacts you and try to focus on what is most affecting you right now. You are the expert on your experience. Physical, occupational and speech therapists can help at any stage. Talk to your doctor about building your care team, and asking for referrals for specialists who can help address symptoms that impact your daily life.

5. **Make the most of your PD care appointments.**
Preparing in advance of your PD care appointments will help your care team tailor treatment to your needs and goals. Come prepared with a list of current medications, notes about current symptoms including which ones have the greatest impact on your daily life and at what time of day, and a list of questions for your doctor. Try to bring someone with you to appointments who can help take notes and ask questions. At the end of appointments, ask for clarification if something is unclear and ask for a printed copy of notes or instructions.

6. **Exercise is essential to managing PD.**
There are many things you can do between appointments to help manage PD. Parkinson's Foundation research shows that people with PD who start exercising earlier in their disease course for a minimum of 2.5 hours per week experience a slowed decline in quality of life compared to those who start later. Establishing early exercise habits is vital to managing your PD symptoms. Exercise can help you maintain balance, mobility, and flexibility, as well as reduce the impact of non-motor PD symptoms like depression and constipation.

7. **You can live well with PD.**
By educating yourself about PD, building health habits that include taking care of your mental health, and working with your care team to tailor treatment to your needs, you can lay the foundation to live well with PD. Continue to do the things you love and know that you have amazing resources available to help you on this new journey.

PD Patient Support Group

Meets the third Tuesday of every month from 2:00PM-3:30PM.

Caregivers Support Group

Meets the first Wednesday of every month from 2:00PM-3:30PM.

Deep Brain Stimulation (DBS) Information Sessions

Meets the first Friday of every month from 3:00PM-4:00PM.

To register for our support groups, and/or our DBS information sessions, please contact Erika Adelman, LCSW, SIFI at 929-695-0282.

Music and Movement Virtual Concert Series

Meets the first and third Wednesday of every month from 5:00PM-5:45PM. To register, please contact Hannah Lee at 212-305-9718.

Speech for PD

Meets every Tuesday and Thursday from 11:15AM-12:30PM. For more information and to register please contact Gemma Moya-Gale, Ph.D., CCC-SLP at gm2446@tc.columbia.edu.

Getting involved in support groups and programs such as the ones listed above as well as on the back, are opportunities to be a part of a community where you can get support, learn from others, be yourself, feel better understood, and you will be able to feel a sense of belonging. These programs can also help you cultivate self-esteem, personal growth, inspiration, and hope for the future!

ColumbiaDoctors Neurology

Parkinson's Foundation
CENTER OF EXCELLENCE

NewYork-Presbyterian
The University Hospital of Columbia and Cornell

Center Spotlight : New Adjustment Disorders Group

What is this group about?

This is a class that we are offering for people who are struggling to adjust to their diagnosis so that they can learn to thrive and persist despite their Parkinson's Disease. During these classes, participants will be provided with tips and tricks to enhance their quality of life with Parkinson's Disease.

Who can participate?

Individuals who have been diagnosed with Parkinson's Disease within the past 9 months.

What is involved?

This is an 8-week class that will be meeting remotely from 12-1pm on Thursdays. The information presented each week will build on information covered in the previous week. Therefore, it is important that you participants attend as regularly as possible.

How much will cost?

Individuals who participate will be billed through their insurance carriers.

For more information:

Please ask your provider to submit a consult to Dr. Micah Savin via EPIC ,or email Dr. Savin directly at ms6870@cumc.columbia.edu.

Division of Movement Disorders
Columbia University
Irving Medical Center
710 West 168th Street
New York, NY 10032
212-305-1303
www.columbianeurology.org/patient-care/movement-disorders

Parkinson's Foundation National Hotline:
1-800-473-4636

Make a Gift--Make a Difference

Wish to Donate?...

Should you be interested in discussing how you can help support our clinical, research, and patient care activities, please contact Matthew Reals, Senior Director of Development, at **212-304-7203** or mr3134@columbia.edu.

Parkinson's Unity Walk

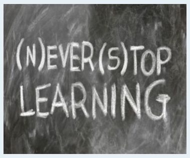
The annual Parkinson's Unity walk is scheduled to be held on Saturday, April 27, 2024 Central Park. 100% of donations support Parkinson's disease research funded by four major U.S. Parkinson's foundations.

Walk a short loop through Central Park and then visit the partner alley booths for information about Parkinson's disease and other resources. Those who can not make it to NY, check out the Unity Walk website for virtual day-of activities, videos, and events. For more info, visit www.unitywalk.org.

To join team CUMC and walk with our the Columbia group, please go register by going to: https://give.michaeljfox.org/team/572094, or type Columbia University Irving Medical Center in the team search. If you need help registering, contact Erika at era2142@cumc.columbia.edu.

NewYork-Presbyterian's 2024 Annual Parkinson's Disease Symposium

Our annual Parkinson's Disease Symposium is scheduled to be held on May 6th & May 7th from 11AM-2:30pm for individuals, caregivers, and community partners, and on May 8th from 6:30PM-9:30PM for physicians and allied health professionals. This year's event will be a virtual symposium led by staff from NYP-Brooklyn Methodist Hospital, NYP-Weill Cornell Medical Center, and NYP -Columbia University Irving Medical Center who are coming together to share their knowledge on some of the newest updates in Parkinson's Disease. More details will be sent out via email soon.



If you have a question regarding Parkinson's and its treatment that you would like featured in the next newsletter, please e-mail your questions and/or inquiries to Erika Adelman, LCSW, SIFI at era2142@cumc.columbia.edu.

The information published in this newsletter is not intended to replace, and should not be interpreted or relied upon, as professional advice, whether medical or otherwise. Please refer to your own professional for all advice concerning legal, medical, or other matters published in connection with this article.

> *"Don't count the days, make the days count."*
> ***-Muhammad Ali, diagnosed with PD in 1984***