



Mental Health, Parkinson's, & the Role of the Care Partner

In July 2020 the World Parkinson Coalition® held the second in its Care Partner Virtual Panel Webinar Series. Julie Carter, RN, MN, ANP and Professor Emeritus at Oregon Health & Science University moderated the webinar on Mental Health and the Role of the Care Partner. She began by welcoming viewers from around the world and reminded everyone that each viewer has a unique perspective and is at a different point in their Parkinson's journey. During this virtual panel, four experts offered advice for Care Partners (CPs) related to the mental health issues that most commonly arise for People with Parkinson's (PwPs).

The Movement Disorder Specialist

Gregory Pontone, MD, MHS

Johns Hopkins University School of Medicine

Mental health conditions are a common cause of problems for PwPs. They are diagnosed at a greater rate than the general population, making early recognition and treatment key to maintaining the best quality of life possible. Mental health conditions for PwPs are typically a biological part of the disease, as opposed to an emotional reaction to the stressors that accompany such a disease.

Here is a brief outline of the mood disorders most commonly affecting the PD community and common treatments.

Anxiety – worry, rumination, retreating from life, physical symptoms (quicken heart rate or breathing), or exacerbation of PD symptoms¹

- Because it is biologically related to the PD and its treatments, anxiety often cycles with a PwP's medications.
- Tracking and journaling anxiety can be helpful in determining triggers and treatments – e.g., medication changes or additions, cognitive behavioral therapy.

Depression – feeling hopeless or negative, often manifesting as a decrease in cognition, interests and energy

- Its effects can have double the impact of physical symptoms on a PwP's quality of life,² but it is easy to treat.
- Treatment often involves medications (many available) and/or cognitive behavioral therapy.

Apathy – feeling nothing

- It is treated differently from depression, and often with cognitive medications (acetylcholinesterase inhibitors).
- A structured routine can include exercise and social interaction and give the PwP something to look forward to.

Impulse Control Disorder – compulsive behaviors like hyper-sexuality or compulsive gambling, buying or eating

- This disorder is typically linked to dopamine agonists (DAs), which affect 10-15 percent of PwPs taking them.
- It is often addressed by discontinuing the DA, but behavioral interventions can help.

Psychosis of PD – hallucinations (including tactile), delusions (false fixed idiosyncratic beliefs)

- There are a number of pharmaceutical interventions that can help.

As a Care Partner (CP) who notices mental health symptoms, here are the recommended first steps:

- Don't panic, and remember there is help available.
- Make everyone on your PwP's medical team aware of what you're observing, as the cause may not be related to PD.
- Investigate and journal potential triggers.

The Parkinson's Educator

Allison Marie Allen, MSW, LCSW

Duke University Medical Center

When left unaddressed, changes in mood due to Parkinson's disease can lead to a decrease in quality of life. As a Care Partner, helping your loved one to stay ahead of and manage these symptoms is a proactive step towards combating caregiver fatigue. Knowledge

and communication are critical not just for the care of the PwP, but for the health of the relationship.

Anxiety will affect at least one-third of all PwPs.³



Things CPs should understand and consider:

- It's time to seek help regarding mental health when symptoms have a persistent or pervasive impact on quality of life. CPs are often the first to notice.
- A PwP's mental health issues frequently are most challenging for their CP, so it's critical for you to be patient with yourself, honor what you need to maintain balance, honor the relationship you share with your PwP, and make self-care a priority.



Things to consider when communicating about mental health issues:

- Talk with your PwP about concerns prior to raising them with your medical team.
- Establish good communication habits early, before more difficult conversations are required. For example: Be mindful of time of day and environment. Don't talk over your PwP or make assumptions.
- Facial masking can complicate communication, but there are activities (singing, mirror exercises, etc.) and therapies (speech therapy, LSVT techniques) that can help.
- Your PwP's medical team is often waiting for the PwP or CP to bring up mental health issues, and once you do they can help.

The Person with Parkinson's

Karen Sauer, *Diagnosed in 2007*

The things she's learned about managing mental health and PD:

- A PwP's mental health affects their CP as much as it affects the PwP.
- Exercise has a positive effect on mental health.
- Maintaining a connection to the activities and interests that offer both the PwP and CP balance and joy, even if adaptations are required, can help immeasurably.
- Don't be afraid to seek professional help (therapy).
- PwPs, be grateful for your CP and all they do. Even if their reminders are sometimes annoying, they may help you to function better. CPs, when you offer these reminders, please do so gently.
- *Figure out what matters to you and communicate it. Don't make your CP guess.*

The Care Partner

Fred Winston

Advice for CPs related to their PwP and mental health:

- *Observe your partner thoughtfully, communicate with them, and adjust as needed.*
- Know what helps your PwP cope.
- Little things can make a difference.
- Control what you can control, but know what you can't.
- Be patient.
- Plan ahead.
- Go to your PwP's medical appointments.
- Make time to talk.
- Do things that you enjoy and maintain interests and projects outside of your CP responsibilities.
- Eat healthy, but also eat butter if it makes you happy.
- If you're not feeling supported by your PwP, have faith in the relationship and seek a good time to have a frank conversation about your needs.



"As a Care Partner or Person with Parkinson's, you should not be trying to manage this on your own. Safely managing these symptoms really does take a team."

— Allison Marie Allen,
Duke University
Medical Center

Watch the Webinar

www.worldpdcoalition.org/carepartner

Tools and Resources Mentioned by the Panelists:

Caregiver Self-Assessment — Parkinson's Foundation:

<https://www.parkinson.org/pd-library/worksheets/caregiver-self-assessment>

Speech Therapy and the SPEAK OUT! Program — Parkinson Voice Project

<https://www.parkinsonvoiceproject.org/OurSpeechTherapyProgram>

- 1 Pontone GM, Dissanayaka N, Apostolova L, et al. Report from a multidisciplinary meeting on anxiety as a non-motor manifestation of Parkinson's disease. *NPJ Parkinsons Dis.* 2019;5:30-8. eCollection 2019.
- 2 Parkinson's Outcome Project, Parkinson's Foundation — <https://www.parkinson.org/research/Parkinsons-Outcomes-Project>
- 3 Prevalence of anxiety in Parkinson's disease: a systematic review and meta-analysis — <https://doi.org/10.1002/mds.26643>

This resource was made possible with support from US WorldMeds and Adamas Pharmaceuticals.