



Parkinson's Foundation Palliative Care Newsletter

July 2023





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Palliative Care Project Updates & Upcoming Events

1. Care Partners: Why They Matter and Why Their Needs Matter

- Our 2023 palliative care educational series for people with Parkinson's and their families is airing throughout 2023 via Parkinson's Foundation PD Health @ Home. On August 9th, 2023, from 1:00pm to 2:00pm ET, we are featuring the episode, *Care Partners: Why They Matter and Why Their Needs Matter*. People with Parkinson's and families can register for the episode using the link [here](#). You can also access the recordings of the past episodes on the Parkinson's Foundation YouTube page [here](#).

2. Invisible Symptoms: Non-Motor Symptoms

- On August 16th, 2023, from 1:00pm to 2:00pm ET, we are featuring the episode *Invisible Symptoms: Non-Motor Symptoms* via Parkinson's Foundation PD Health @ Home series. This video will give an overview of non-motor symptoms that can be related to Parkinson's and how to communicate these symptoms to medical teams to improve the medical care being received. This talk also discusses ways to improve care coordination and communication across teams of medical providers. People with Parkinson's and families can register for the episode using the link [here](#).

3. Advance Care Planning Video

- The advance care planning video, "Preparing for Your Future," that you were provided access to in a folder expired on July 19th, 2023. The video is now available [here](#) on the Foundation's YouTube channel. Please use the YouTube link moving forward to share the video with people with Parkinson's and their families.

4. Palliative Care Interviews

- Know of a physician or advanced practice provider who would be interested in sharing their experiences with palliative care implementation and delivery in a brief, one-time interview? If so, please reach out to mdini@parkinson.org for more information. Thank you for all of the participants we have interviewed!

Palliative Care Resources & Tips

1. PD Conversations!

PD Conversations is a Parkinson's Foundation webpage where Parkinson's patients can ask questions, connect with others living with the disease and be part of a network of support. Participants can join discussion groups to connect with others and also receive helpful answers to Parkinson's questions from the Parkinson's Foundation Helpline. Access this excellent resource and community [here](#).

2. CareNav

CareNav is a simple, user-friendly tool designed to help families navigate the complexities of the care partner journey. This tool can help connect families with expert fact sheets, informative videos, and local resources. Learn more on how CareNav can provide help to care partners [here](#).

3. Parkinson's Foundation Care Partner Burnout Course

Care partner burnout, a state of physical, emotional and mental exhaustion, happens when care partner try to do too much for too long. This course will help care partner recognize and understand ways to prevent and address both care partner strain and burnout by recognizing their limits and setting boundaries. You can access the course [here](#).



Center Spotlight: Palliative Care COE Implementation

Parkinson's Pals: A Student-Led Program for Persons with Parkinson's Disease

Om Gandhi, Jaskeerat Gujral, Whitley Aamodt, MD, MPH, MSCE, PC Champion, The Parkinson's Disease and Movement Disorders Center of the University of Pennsylvania

Parkinson's disease (PD) can lead to feelings of loneliness and demoralization that have a detrimental impact on quality of life and require innovative treatment strategies. To improve psychosocial well-being among persons with PD, undergraduate students at the University of Pennsylvania created Parkinson's Pals, a student-run organization that facilitates 1-on-1 intergenerational connections between undergraduate students and persons with PD. Patients are referred for participation in Parkinson's Pals by their movement disorders specialist during routine PD and palliative care clinic visits. All patients who are interested in participating are contacted by Parkinson's Pals leadership. Patients are matched with student volunteers based on personal and professional interests and hobbies. After the matching process, all students undergo an educational and clinical training session provided by the Davis Phinney Foundation, which teaches students about PD and the appropriate way to interact with patients. Then, each student and their pal meet virtually 2-4 times monthly for one hour. Discussions often involve childhood stories, shared interests and hobbies, career aspirations, and lived experiences. While all PD patients are eligible to participate, the program was specifically created to help patients who are socially isolated or live alone.

Parkinson's Pals has been active for 1.5 years and has expanded to 9 universities in the United States. Over 250 students have expressed an interest in volunteering, and patient enrollment is increasing as chapters partner with local PD clinics. We conducted a short pilot study at the University of Pennsylvania from March to July 2022 and collected feedback from 7 student and patient pairs. Students felt the program was an excellent outlet for inspiring, educating, and connecting younger generations with older adults. Patients also appreciated the program and their ability to form new and lasting friendships. Notably, 6 of the 7 students continued meeting with their pal following the mandatory 6-week period. We believe this program can treat the often overlooked psychosocial symptoms of PD, while also helping students strengthen their communication skills and gain valuable insights into the social and neuropsychiatric dimensions of PD.

We hope to expand Parkinson's Pals to universities worldwide, potentially integrating this model into undergraduate or medical school curricula. We also plan to measure the impact of the program on psychosocial well-being and mood symptoms in PD by administering surveys and validated questionnaires before and after program participation. If you would like to learn more or start a chapter at your institution, please visit the program website at: <https://www.parkinsonspals.org/>.



Supporting Care Partners at Cleveland Clinic

By Taylor Rush, PhD, Clinical Health Psychologist, Center of Neurological Restoration, Cleveland Clinic

1. How do you support care partners of people with Parkinson's disease? What are some of the ways you work with the Parkinson's center providers?

I am a clinical health psychologist in our Parkinson's Center of Excellence at the Cleveland Clinic. I am an embedded psychologist, which means that I work side by side with my neurology colleagues, along with other services such as social work, psychiatry, physical therapy, occupational therapy, and speech therapy. Together, we create comprehensive treatment planning for our patients to provide the best care possible. I work with individuals who have been diagnosed with Parkinson's disease, as well as their surrounding support system, to address issues including depression, anxiety, adjustment to Parkinson's symptoms, and ways in which care partners can provide the best support possible while also caring for themselves.

2. For many centers, providing support for care partners is difficult because they are not the primary patient and billing can be challenging. How do you manage that?

As a center of excellence, we are fortunate to be able to provide support to care partners via case management services by our social workers. This allows us to help them meet many of the instrumental and logistic needs that they may have. In addition, we have received grant funding in the past to allow for additional services such as group support for care partners. I also accommodate slots for care partners on my schedule and bill separately under their insurance plan.

3. What are some of the programs you provide or connect care partners of Parkinson's patients to?

I and our center of excellence coordinator, Ellen Walter, CNP, created a care partner symposium in 2019, called care partner U. This is a daylong event geared towards the empowerment and well-being of care partners to those with PD. The goal of this event is not just to give them tools and education on how to be better care partners, but also how to best take care of themselves. Because we understand logistical challenges that care partners may face, we also offer programming and support for the person with Parkinson's in a separate room, so that all may benefit from the day. We've been told that offering this has allowed many people to join our event that otherwise would not be able to.

In addition, we piloted an 8-week care partner support group during the pandemic, which was an incredible success. We are now planning an ongoing support group that can be accessed by our care partners as needed throughout the Parkinson's journey.

Lastly, we have an interdisciplinary palliative care clinic for patients with more advanced PD symptoms, or they meet with a neurologist, a palliative medicine physician, and social worker. This allows us to comprehensively assess and discuss medical, psychological, and instrumental needs that the person with Parkinson's as well as their care partner may have.

4. Do you have any advice for screening and managing care partner needs?

First off, make sure you do it! Oftentimes, even the care partner does not have their needs on the radar when they come in for medical visits. Therefore, it is important for providers to ask them pointed questions about their needs. Sometimes, if space allows, it can be helpful to do this in a room separate from the person with Parkinson's or provide a questionnaire ahead of time that the care partner can fill out that allows them to freely discuss some of their own challenges or needs.