



Parkinson's Foundation Palliative Care Newsletter

August 2023





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Palliative Care Project Updates & Upcoming Events

1. Upcoming Town Hall on Care Partner Assessment & Support

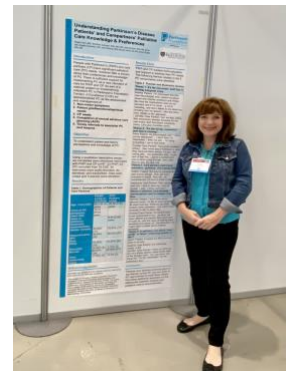
- We are hosting a palliative care town hall on screening for and addressing care partner needs on **Wednesday, September 20th at 3pm ET.** This town hall will be led by Dr. Janis Miyasaki, the University of Alberta, and will include how to integrate screening of care partner needs and identify appropriate support. We sent out the calendar invitation last week. Please forward it to other team members who might be interested in attending.

2. “Your Voice, Your Values,” a Course for the PD Community Now Available on YouTube

- Our full course for the PD community on palliative care topics is now available on the Parkinson's Foundation YouTube channel. This course features topics related to how you can make your voice heard and improve the quality of your care. You can access the course [here](#). Please use the YouTube link to share the videos with others who may be interested and wish to learn.

3. Presentation on Understanding Parkinson's Disease Patients' and Care Partners' Palliative Care Knowledge & Preferences

- Nicole Yarab, Parkinson's Foundation, recently presented a poster related to our Palliative Care project at the International Congress of Parkinson's Disease and Movement Disorders in Copenhagen, Denmark. This study was completed in collaboration with the University of Rochester. The study aimed to understand prior to the project implementation the Palliative Care knowledge and preferences of persons with PD and their care partners from our Centers of Excellence. Key findings include a preference for more education and support on addressing palliative care needs as well as a need for increased guidance and support for care partners. You can access the poster [here](#). Passcode 7RVb8eT8.



Palliative Care Resources & Tips

1. Caregiving Through the Progression: Themes from Parkinson's Care Partners through early, mid-stage, and advanced Parkinson's

The Parkinson's Foundation conducted interviews with three Parkinson's care partners for the Care Partner Program online course “Caregiving Through the Progression.” You can access an article [here](#) that highlights the unique experiences of a diverse group of care partners throughout their Parkinson's journey. Passcode for the article is XhSsa9vg. You can also access the course [here](#).

2. Caregiver Burden in Parkinson Disease: A Scoping Review of the Literature from 2017-2022

This scoping review of the literature from January 2017 through April 2022 provides an updated evidence-based summary of patient and caregiver-related factors that contribute to caregiver burden in Parkinson's Disease (PD). A description of recent interventions to mitigate burden is also provided. Access the article [here](#). Passcode SkMRnFk9.

3. Resources for Care Partners

Parkinson's disease progresses over time and so does the care partner role. Explore all stages of the care partner journey and practical tips that can help along the way. You can access the information [here](#).



Vignettes from the Parkinson's Foundation Helpline on Supporting PD Care Partners

We reached out to the Parkinson's Foundation Helpline to share examples of how they support care partners. Here are some examples:

- Care partners of people with chronic, progressive illnesses do not experience tangible results from their efforts. In fact, the very opposite is true – despite all of their work, their loved one gets worse. And the worse a patient gets, the more advice the care partner gets about what they should be doing, which makes them feel that they are somehow responsible for the decline. The two most important messages a care partner needs are:
 1. This is really difficult work AND you are doing a great job.
 2. You also have needs and your needs matter.
- A woman called the Helpline completely exhausted and stated that her husband with Parkinson's told her if she didn't start sleeping in his bed, he would divorce her and kick her out of the house. She had moved into a separate bedroom 3 years prior because her husband has lots of sleep issues and she is a light sleeper. The information specialist provided supportive listening and normalized the conversation. This helped the caller disclose feelings of guilt for not wanting to sleep with or be sexually intimate with her husband. She felt this legitimized his right to divorce her. The information specialist was able to help the caller verbalize how her husband's cognition/behavior/mood had been impacted by Parkinson's disease over the years. By listening and linking his behavior to the disease, the information specialist not only provided needed support but also recommended seeking the help of a counselor and gave her a list of counselors who accept her insurance.
- A care partner of a person with PD called our helpline for ideas on how to manage her husband's mood changes and anger outbursts. She was tearful, overwhelmed and felt 'hopeless'. We discussed the idea of joining a local care partner support group, finding a counselor for both the person with PD and herself, talking to their neurologist, and asking family for additional support. At the end of the conversation she said, 'It's just so nice to have someone to call and talk to.' While the resources we provide are helpful, the impact of talking to an empathetic, compassionate person is invaluable.
- A care partner called the Helpline distraught because several people told her she needs to divorce her husband in order for him to get government funded care. The information specialist was able to provide supportive listening, reassurance, and sent her a list of elder law attorneys in her area who specialize in Medicaid planning to explore options and next steps.



Vignettes from the Parkinson's Foundation Helpline on Supporting PD Care Partners

- A distraught care partner in her 80s called for help related to 86 year old husband's skin problems. He had been tearing his skin because it was itching at night. She had tried everything to no avail. The nurses at his nursing home had also tried different topical treatments and were finally giving him morphine to calm him down.

Our helpline specialist explained the effects opioids and encouraged her to talk to the doctor about alternative medications. She was encouraged to talk to the doctor and seek a consult with a dermatologist.

It was apparent that she was under a lot of stress and the specialist offered to identify a counselor who would be covered by her insurance. The specialist also suggested joining a support group that the social worker at her husband's facility had recommended. At the end of the conversation, she felt supported and agreed to reach out to the social worker.

The Parkinson's Foundation Helpline welcomes calls from people with Parkinson's disease, their families, friends and health care providers at 1-800-4PD-INFO (1-800-473-4636) or Helpline@Parkinson.org.

Vignettes from a Care Partner on Palliative Care

Linda Hall, a care partner on our Patient and Care Partner Advisory Council talks about the benefits of palliative care in the passage below:

My husband and I have been involved with Palliative Care (PC) as a patient and care partner for almost six years. As I attend (except dental) his medical related appointments, I have observed and been a recipient of the supportive care that PC provides. For me, the most notable comparison between PC and standard care appointments is that I feel I am being treated as part of the "team". I am encouraged to provide input and I feel as if I am being heard and appreciated for my opinion and perspective. Medical appointments can invoke anxiety, yet I leave PC appointments comforted and reassured.

I have personally benefited through an unanticipated PC outcome. Through our PC experience my husband feels supported, validated, comforted, and hopeful. As a care partner, that is a gift I welcome.