



# **Parkinson's Foundation Palliative Care Newsletter**

**February 2023**





## **Palliative Care Project Updates**

### **1. Palliative Care Town Hall on Spirituality on March 22<sup>nd</sup>**

- Our next palliative care town hall will be taking place at 1 pm ET on March 22<sup>nd</sup> on Spiritual and Emotional Needs. You will hear about topics such as understanding spiritual distress, integrating consistent chaplain support, distinguishing grief from depression, and involving and referring to psychiatry. There will be an interactive Q&A at the end of the program. Please follow-up if you have not received the invite.

### **2. International Palliative Care Society (INPCS) Conference**

- Registration for the conference that took place on November 10<sup>th</sup>-12<sup>th</sup> has re-opened for on-demand access to all of the wonderful conference content. With the coupon code DEMAND22, people who register now will receive 25% off the regular rates. You can register [here](#).
- Save the date! The next INPCS conference, *Coming Together to Transform Care*, will be taking place in person in Minneapolis from September 12<sup>th</sup>-15<sup>th</sup>.

### **3. Registration Information for the Palliative Care PD Health @ Home Series**

- Our 2023 palliative care educational series for people with PD and their families continues, with the most recent episode, *"Making Sense of it All,"* on spiritual and emotional needs by Dr. Sue Ouellette, University of Rochester. This series will continue airing throughout 2023 via PD Health @ Home through the Parkinson's Foundation. You can access the recordings of past episodes on the Parkinson's Foundation YouTube page [here](#). Further, using this [link](#), people with Parkinson's and their families can register for entire series. Dr. Farrah Daly will be presenting next on hospice on Wednesday, May 3<sup>rd</sup>.

## **Palliative Care Resources**

### **• Meditation Resources by Sue Ouellette, Ph.D., M.Div., MA**

Click [here](#) for a useful list of meditation resources that people with PD and care partners can access to learn more about meditation and how to integrate it into their daily lives. Passcode: AunJEq7t

### **• Grief Resources**

Access this [website](#) for useful resources by world renowned expert, David Kessler, on grief. This resource is dedicated to helping people deal with the often unknown terrain that comes with grief through education, information and other helpful resources. You can also click [here](#) to download a grief journal.

### **• Parkinson's Foundation Care Partner Program**

The Parkinson's Foundation Care Partner Program is a series of self-paced free online courses designed with care partners in mind and is recommended for anyone caring for someone living with PD, including spouses, partners, parents, children, friends or other family members. You can recommend this resource to care partners. [Here](#) is the registration link.



## **Question and Answer: Addressing Care Partner Needs**

By Adriana Gonzalez, LCSW, Palliative Care Champion, UC San Diego Parkinson & Other Movement Disorder Center (UCSD) and Janis Miyasaki, MD, Med, FRCPC, FAAN, Palliative Care Project Coach

We asked Adriana and Dr. Miyasaki some common questions posed during coaching meetings on how to address care partner needs. See their responses and suggestions below.

**Question: If someone is challenged by what steps to take if a care partner screening is positive, what would you recommend they do next?**

Adriana Gonzalez: My go-to for working with care partners or introducing myself to them is a gentle check in. I would say something similar to, "I noticed that in your screening you reported feeling more irritable than usual." It really is about building a relationship with our care partners, reminding them that they are an important part of the care team. They may not feel that it is appropriate to talk about their needs in a clinic setting or medical appointment, so I try to schedule a phone check-in. Providing person-centered care means that we "meet people where they are." Allowing them to guide our conversation, it starts with a conversation, and we try build from there.

Dr. Miyasaki: A great social worker is very helpful. Another option is spiritual care if the issue involves dealing with distress, hopelessness, frustration, or exhaustion. If the caregiver's primary care provider (PCP) is also the patient's PCP, I will call the PCP to say in the course of the appointment, I noted this- with caregiver permission - and the PCPs are always grateful. Many centers have a caregiver support group, and this can also be helpful.

**Question: What types of resources can be helpful for addressing care partner needs? If a center does not have care partner resources available at their institution, what steps can centers take to form relationships in the community? What types of community relationships would be valuable?**

Adriana Gonzalez: The first step in addressing care partner needs is to acknowledge their importance on the care team. Often care partners feel alone in their journey so we can be those people who acknowledge and validate their experiences. In social work we talk a lot about "person in environment," so I encourage care partners to build up their own care network. Whether that be good friends, family, a support group or a therapist, there are many ways to create support. Our role in working with care partners is to remind them that they matter too, their health matters, their spiritual and emotional wellness matters and to plant that seed that self-care is not selfish.

As a center we cannot do it all. We must rely on our community partners to be effective and address the broad spectrum of care partner needs. A support group does not have to be one we run within our institution: there are Facebook groups, virtual national groups, local groups for care partners that are not PD specific. I encourage social workers to connect with their community. Get to know your local area on aging or your local family caregiver resource center. They may not be Parkinson's specific, but it is an opportunity to collaborate with local resources. I sit on several county level committees and advisory boards where we work to establish programming for family caregivers. It gives me the opportunity to meet dementia care specialists, local assisted living activities directors, and all of those connections matter because I can learn as much from them as they can from me. We can improve care for people living with PD and their families by understanding what is available and educating the community on the unique needs of people with PD and their care partners.

Dr. Miyasaki: Holding or encouraging attendance at a caregiver support summit can be helpful, as well as connecting the care partner with the [Parkinson's Foundation Helpline](#), [educational materials](#), or identifying a local caregiver association in the area.



## Stoplight Poster for Care Partners

By Antonia Pusso, MD, Palliative Care Champion, University of Colorado Movement Disorders Center

Wondering about different ways to screen care partners?

The University of Colorado Movement Disorder Center has stoplight forms (displayed below) on their clinic doors prompting caregivers to discuss their needs with providers. A PDF version can be found [here](#). Passcode: H8AiDt69

# AS A CARE PARTNER, HOW DO YOU FEEL?

**I feel stressed/overwhelmed, worn out, do not know what to do about the loved one I care for, or do not have time for myself.**

