



Parkinson's Foundation Palliative Care Newsletter

April 2023





Palliative Care Project Updates & Upcoming Events

1. New Parkinson's Foundation Palliative Care Webpages

- We are pleased to share that the Parkinson's Foundation Palliative Care webpages are now live on our website. We hope these webpages can help discussions with people with Parkinson's and their families about what palliative care is and how it can be beneficial to anyone with PD. You can access the webpages by following the navigation instructions and links below.
 - Accessing the Webpage for the Community - **Living with Parkinson's > Our Care Programs > Palliative & Supportive Care**
 - Accessing the Webpage for Professionals - **Resources & Support > For Professionals > Quality Care Initiatives** (listed along with Access to Care and Hospital Care initiatives)

2. Upcoming Educational Event: Things to Know About Hospice Care for People with PD

- This event is a part of the Palliative Care Wellness Wednesday's series for the larger Parkinson's community and their families. During this session, Farrah Daly, MD will provide an introduction to hospice that will cover topics like what hospice is, what services hospice can provide, and a review of the typical timing of hospice. There will also be discussion on how to select a hospice program to address personal needs and how to be an advocate when receiving hospice services. The virtual zoom event will take place on May 3rd, 2023 from 1:00- 2:00 PM ET. Attendees can register [here](#).

3. Upcoming Palliative Care Townhall

- We have sent out the calendar invite for our next palliative care town hall on **June 7th 1-2pm ET** on Collaboration and Support with Hospice and Palliative Care. This event will be led by Christina Vaughan, MD and will include additional speakers. Please forward the invite to other team members on your team!

Palliative Care Resources & Tips

1. Registration Open for International Neuropalliative Care Society (INPCS 2023)

Three days of informative speakers, engaging panel discussions, and productive networking with neuropalliative care thought leaders from around the world. The 2023 INPCS conference will take place September 12-15 in Minneapolis, Minnesota. For full details about the conference, or to register, click [here](#).

2. Opportunity for Research Study Participation: How People Use Religion to Cope with Parkinson's

There is an opportunity for people with Parkinson's to participate in a research study that aims to understand if and how people with Parkinson's use religion, faith, or spirituality to cope with their illness. To participate in the study, you must be diagnosed with Parkinson's, age 18 or older, reside in the US, and also able to speak and read English. Participants will receive \$150 for participating. You can access the flyer [here](#). Passcode: 2FFDkQgK. You can also go to the study website directly to learn more [here](#).

3. Getting Your Affairs in Order Checklist: Documents to Prepare for the Future

This resource contains a checklist and guide to help patients and families be prepared for the future. It details the items and steps for how to get their affairs in order and gather all of the needed information to ensure their wishes are honored and ease the burden on loved ones. Access the resource and check list [here](#).



Center Spotlight: Palliative Care COE Implementation

Narrative Medicine in Parkinson Disease

Sneha Mantri, M.D., Palliative Care Champion, Duke Movement Disorders

Narrative medicine is a branch of medical humanities that focuses on storytelling as a form of connection between patients and clinicians. First articulated by Dr. Rita Charon in 2011, narrative medicine programs have flourished in healthcare spaces across the world. As a medical student, I found narrative medicine to be an antidote to the burnout and moral injury I experienced during my clinical rotations. By refocusing my attention on the patient and their story, I was able to reconnect with the values that brought me into medicine and keep me grounded to this day.

Within Parkinson's care, narrative medicine and qualitative research is critical in centering the voice of the patient in everything we do. One of the components of our interdisciplinary care clinic is the "55-word story." Patients are given a notecard or an iPad and asked, "What is most important for your care team to know about you?" By leaving the question open-ended, patients can guide the agenda for the visit to the most important issues for them. Some patients have commented specifically on Parkinson's-related issues, such as mobility or communication challenges; others have shared information about the support networks in their lives or values that are important to them. We are currently analyzing whether demographic or clinical characteristics, like age, sex, or disease duration, influence patient storytelling. We are also looking at the relationship between patient story and validated quality of life measures.

Narrative medicine and palliative care have a long tradition of synergy, and it is exciting to bring this technique into Parkinson's care. Some specific recommendations for the PD populations include ensuring that multiple modalities are available to capture the patient's story (e.g. speech-to-text, typing, writing) and recognizing that the illness narrative will shift with disease progression. On a logistical level, it has been extremely helpful to have a student, clinic coordinator, or nurse "assigned" to collect the story (e.g. log in to the iPad or ensure the notecard gets to the correct provider). We also decided to keep the stories very short—these are conversation openers, not a formal advance directive. Nevertheless, the 55-word-story has become an integral part of our clinic operations. Centers who are interested in implementing similar projects or learning about continuing education opportunities in narrative medicine can contact me directly.

To read more about narrative medicine in palliative care, you can access this recently published commentary in *Neurology Clinical Practice* by Esme D. Trahair, BA and Sneha Mantri, M.D. [Access it online.](#)

You can contact Sneha Mantri, M.D. through email at sneha.mantri@duke.edu

References:

1. Charon R. The patient-physician relationship. Narrative medicine: a model for empathy, reflection, profession, and trust. *JAMA*. 2001;286(15):1897-1902. doi:10.1001/jama.286.15.1897
2. Stanley P, Hurst M. Narrative palliative care: a method for building empathy. *J Soc Work End--Life Palliat Care*. 2011;7(1):39-55. doi:10.1080/15524256.2011.548046
3. Trahair ED, Mantri S. Examining the Role of Narrative in Palliative Care for Parkinson Disease: Changing the Story. *Neurol Clin Pract* 2023 (in press).



Question and Answer:

Answered By: Farrah Daly, MD

Question: Once admitted to home hospice, are patients still able to see our providers in the practice for follow-up care or does this threaten the discontinuation of their hospice enrollment?

Answer: Hospice is a system of care that affects payment for medical services. When a person enrolls in hospice, the hospice becomes financially responsible for all of the person's care related to their declining health. This includes medications, durable medical equipment, interdisciplinary team services from social work, spiritual support, and volunteers, and medical support from nursing and a hospice physician. Insurance will continue to pay for medical services from one additional physician or advanced practice provider who is officially named as the "attending of record" for this hospice team. The "Attending Physician" will need to review hospice orders and paperwork and can continue to see the patient and bill insurance for their services using a special modifier code on their bill. Many times, the "Attending Physician" is the primary care physician, however it is possible for it to be the neurologist (and this may be especially appropriate when the main health problem is neurologic).

If a person enrolled in hospice care would like to or need to see a specialist consultant, like a neurologist, who is NOT the "Attending Physician" then it is still possible, but it requires a bit of work and coordination. There needs to be a contractual arrangement made between the specialist and the hospice in order for the specialist to be paid for their services. Many hospices are willing to make this arrangement however some are not. It requires coordination and advance notice. This is a great thing to ask a hospice organization about PRIOR to signing up for services, since their willingness to contract with a specialist may vary.

Rarely, if a person's health is declining from a condition that is ENTIRELY UNRELATED to their neurologic condition, then they can still see the neurologic specialist for the unrelated condition without any special arrangement. This is pretty uncommon.

Community Partners in Parkinson's Care

The Parkinson's Foundation has expanded the Global Care Network to include a new membership program for senior living communities and home care agencies, Community Partners in Parkinson's Care. The membership program prepares organizations to provide quality education and tools that equip staff to care for people with Parkinson's disease (PD).

Community Partners in Parkinson's Care provides a full curriculum of PD education through virtual and in-person training. Utilizing the train-the-trainer model, the membership program educates site champions at each location and provides the necessary tools to educate at least 70% of site staff. This program, formerly the Struthers Parkinson's Care Network, part of the Struthers Parkinson's Center in Minnesota (a Parkinson's Foundation Center of Excellence), has been continuously expanding and now includes more than 100 member sites across North America.

You can learn more about the program [here](#). For questions about this program and how organizations and networks can become involved, please email communitypartners@parkinson.org.

If you have any questions about palliative care implementation at your center, including any challenges or barriers that your center has encountered, please submit them to Jinnia Nusrat at jnusrat@parkinson.org to be answered in a future edition.