



Parkinson's Foundation Palliative Care Newsletter

June 2023





Palliative Care Project Updates

- **Final Palliative Care Coaching Meetings**

- We are excited to be kicking off the final meetings for the Palliative Care Project. These final meetings are taking place from June 2023 to September 2023. They are one hour individual center meetings. We are sending out a survey for one person from each team to complete ahead of the scheduled time. This survey is an important piece of our data collection. We hope the final meeting helps you set future goals for palliative care.

- **Palliative Care PD Health @ Home Series**

- 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 July 12th, 2023 from 1:00pm to 2:00pm EST, we are showing the episode, *Preparing for Your Future: Advance Care Planning, Goals of Care*. Using the link [here](#), people with Parkinson's and their families can register for the episode. You can also access the recordings of past episodes on the Parkinson's Foundation YouTube page [here](#).

- **June Palliative Care Town Hall**

- Thank you to everyone who joined our June palliative care town hall on Collaboration and Partnership with Hospice & Palliative Care. The event was led by Christina Vaughan, MD, University of Colorado who gave an overview of hospice. Muhammad Nashatizadeh, MD, University of Kansas School of Medicine talked about building a palliative care partnership, and Nicole Cool, BSN, RN, Medical University of South Carolina talked about hospice care collaboration and referrals at their center. Please access the town hall recording [here](#). You can also find the slide deck [here](#). Passcode: 7kzmZnAz

Palliative Care Resources & Tips

- **International Palliative Care Society (INPCS) Conference**

- The next INPCS conference, *Coming Together to Transform Care*, will be taking place in person in Minneapolis from September 12th-15th. This 3-day event, which kicks off with a welcome reception on Tuesday night, will feature discussion panels, speakers, clinical round discussions, great networking opportunities, poster presentations, and so much more. You can register for the conference [here](#).

- **Palliative Care for Individuals with Neurological Diseases**

- Benzi Kluger, MD, Claire Creutzfeldt, MD, and Malenna Sumrall, PhD joined Jonathan Blott to discuss palliative care for individuals with neurological disease and exploring the challenges and opportunities for enhancing the quality of life of those affected by neurological conditions. You can access the podcast [here](#). Their review article is also published in the July issue of The Lancet Neurology. Please access the article [here](#).

- **VITAS Healthcare**

- VITAS brings hospice care to the patient at home. They have an interdisciplinary team comprising a nurse, physician, aide, social worker, and chaplain. They also work with music therapists to meet emotional and spiritual needs of the patient and their families. To learn more about VITAS and their services, access their website [here](#).



What Can You Do to Honor Those Who Died and Support Their Families?

By Benzi Kluger, MD, University of Rochester Medical Center (URMC)

As you get deeper into the palliative care work, you will find that you have more to offer people throughout their illness course and that you will more frequently stay connected to patients as they near end-of-life. So what can you do to honor those who died and support their families? Here are a few suggestions based on my work with teams at Colorado and Rochester:

1. **Condolence Cards:** Sending out a simple but heart felt card, signed by and with messages from the team, can be a simple way to let families know you are thinking about them and an opportunity for closure for your team. At Colorado we had a weekly ritual of signing cards together at the end of our clinic, sharing stories about the person who passed, and ending with a moment of silence and prayer. We hope our positive energy reached the family and felt it was not only healing for our team but helped provide inspiration and reminders of the meaning of our work.
2. **A personal call:** Having someone (or more than one person) on the team who feels moved to reach out with a phone call a few days after a patient's passing is a more direct way to connect. It can allow the team to share how much you will miss seeing the loved one, what you've learned from them, and for the family to share their gratitude or other details. Of note, although hospice does provide bereavement services, sometimes family will want to process their grieving with your team as you have a shared history. In the condolence card at Colorado, we encouraged families to reach out for any questions or need for support.
3. **A Remembrance Ceremony:** Hosting an annual ceremony to remember those who have passed can be a powerful way to allow families to process their grief and for healthcare providers to learn more about the people they cared for. It may not be for every family or provider, but for those who come it can be a very moving experience. At both Colorado and Rochester, our neuropalliative care team hosted this for the entire department, but it could be done on a division level. A simple format would be:
 - a. Welcome and Introductions to the team and service
 - b. Brief remarks from healthcare providers (e.g., sharing how much of an honor it has been to care for these individuals...)
 - c. Sharing of pictures, stories and names collected from families (slideshow with moving music)
 - d. Invitation for healthcare providers or families to speak
 - e. Closing
4. **Philanthropy and Brain Donation:** It may seem crass to mention money and autopsies in this context, but making a brain donation for science or giving a gift in someone's honor can be a way of making meaning of their loss and may be part of the family's healing journey. You want to approach this sensitively and consider working with your foundation officers (or your palliative care department's officers who may have more experience in this domain) to develop an approach to bringing up these topics.

See a previous URMC's remembrance ceremony flyer [here](#). Passcode: tY4yzQiH

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.



Palliative Care Initiatives at BIDMC

By Lissa Kapust, LICSW, Palliative Care Champion, Beth Israel Deaconess Medical Center (BIDMC)

What is a Palliative Care (PC) mindset? The essence of this mindset is having the tools and confidence to engage in thoughtful discussion with patients about anticipated future care and needs. From my perspective, this mindset was launched with the Team-Based Palliative Care initiative offered by the Parkinson's Foundation just two years ago. A lot has changed since that training; yet at the same time our practices will be shaped by the Palliative Care mindset. It's a process.

We worked hard to get most of our PD team enrolled in the training. Now, two years later, with some new staff on board, we are encouraging them to get the training. Several key factors that have allowed for our PC successes. Importantly, we have a dedicated, hospital-based PC team. We have developed an electronic newsletter that now reaches over 2000 people with Parkinson's (PWP) and families; this allows us to disseminate information quickly. Finally, I have a dedicated job as coordinator of "WellnessWorks": an umbrella for a large range of educational and exercise programs offered by BIDMC for patients and families. I will describe each of these components.

The hospital's PC team includes physicians, a nurse practitioner, social worker, nurse coordinator and psychiatrist. The psychiatrist on the team views PD as a "whole body illness" with an approach that demands attention to physical symptoms, coping and care partner support, future care planning and uncovering unmet needs. The PC team is now fully integrated into regular Interdisciplinary Team Clinic (IDC) and they are staffed to accept referrals from providers for regular clinic appointments. Patients are seen in person or virtually. Our COE is grateful that the PC team is now fully staffed and can respond to referrals without too much delay, with the capacity to see PWP over time.

Our e-newsletter has become an indispensable communication tool for promoting all programs. We will be writing a feature spotlight on the PC team for a summer e-newsletter. We have woven PC information into virtual programs such as *My Parent Has PD and I Have Questions* (for adult children), *Learn the Ropes* (intended for new PWP to our COE) and *For and About Women*. There are many ways to inject PC into the conversations!

We offer dedicated PC programs, most recently, *Thursday at the Movies: Everything But The Popcorn!* This program featured the video, "[Preparing for Your Future](#)" featuring faculty at the PC Program at the University of Rochester. An eye-catching [flyer](#), created for the event, was emailed to our large mailing list. We engaged staff to help spread the word. We watched the video, broke up into small groups for discussion, and then brought everyone together for a robust discussion. Feedback from the event tells the story: "I want to watch the video again with family members."; "We need to ask ourselves if we have people to support us and what to do if the support isn't there."; "Video presenters were humanizing, making the questions seem easy and natural." Difficult questions were brought to the larger discussion from the breakout rooms such as what if family members don't agree on an approach to end of life planning and what happens if you lack finances to pay for needed home care. These are complicated questions with answers that need further discussion with the team.



Finally, my job is dedicated to creating and managing wellness programs. Admittedly, this is a luxury for many Centers. It allows me freedom to be creative with programming, write and execute funded grants and step forward as the PC Champion. I will need to consider my role at the end of the PC initiative.

Without the formal title of PC Champion, I hope to continue to consider how to keep moving the team forward, recognizing time constraints for providers. Similarly, I will continue to offer educational programs for our PWP, recognizing resistance to these discussions as well as competing demands on their time.

In closing, a few quotes from staff, to give the flavor of the impact of the PC initiative on them.

What has the impact been?

“The PF Palliative Care training made me more aware and attuned to potential PC-related needs of my PD patients and their care partners. I am now much better about screening for PC needs, and able to better integrate PC specialists into our interdisciplinary team.”

“The training gave me confidence to ask the right questions. The discussion led to several referrals to the PC team.”

“The training has shown me how we can all take charge of our end of life wishes and should take time to have thoughtful conversations with family and doctors about our values and wishes as they relate to quality of life.”

And most importantly, the voices of our patients:

“It has given me great comfort to know about the Palliative Care team at BIDMC. They are caring and compassionate providing a wide range of support to meet you and your loved ones wherever you are on the journey.”

“Consulting with a palliative care clinician has helped my wife and I air out some of those difficult, seemingly unspeakable matters related to the end of life. The topics have ranged from preparing medical directives to profound philosophical questions, an inclusivity that helps by taking into account the lived experience of the whole person, not just a given illness and its treatment.”

Thursday at the Movies: Everything but the Popcorn! A Discussion About Palliative Care

Are you confused by the terms “advanced directives,” “advanced care planning,” or “goals of care?” Does it all seem like jargon? It is confusing! But the terms are important to understand. Join us on **Thursday, May 18 at 3:30PM** and watch the Parkinson’s Foundation video, “Preparing for Your Future.”

Lissa Kapust, LICSW, coordinator for WellnessWorks will be joined by Dr. Aaron Kuntz from the Palliative Care Service for a discussion after the video about how to make informed decisions about your medical care and treatment.

This event will be offered **on Zoom**.

To register, click [here](#) or email Michelle Guo at mguo1@bidmc.harvard.edu

**When: Thursday, May 18th
3:30 - 5:00 PM**
Where: Zoom, Online
The event is free, but registration is required.

