



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

**March 2023**





## **Palliative Care Resources & Tips**

### **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. 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. Daily Care Resources for Patients with Parkinsonism**

- Aaron Daley, MA and team at the University of California – San Francisco published a paper on care resources in the United States for patients with Parkinsonism. You can access it [here](#).

### **3. The Spiritual Considerations of Symptom Management**

- Learn about the exploration of advanced symptom management for those living with serious illness. This video by Sharon Burniston, MDiv, a Palliative Care Chaplain at Overlook Medical Center, focuses on the spiritual considerations of symptom management and how “thinking outside the box” provides an opportunity to address the whole person's needs. Access the video [here](#).

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## **Center Spotlight: Palliative Care COE Implementation**

### **Comprehensive Cognition Clinic at Medstar Georgetown**

Elizabeth Mundel, MD, Palliative Care Champion, Medstar Georgetown University Hospital

We are excited to share some information about our “Comprehensive Cognition Clinic” at Georgetown. We started this clinic as a separate venue to address patients' cognitive concerns given the increasing number of overlapping parkinsonian and cognitive disorders. Prior to the Palliative Care initiative, we used the “CCC” clinic to perform cognitive testing, screen for social work needs, talk about treatment for cognitive disorders and psychosis, and discuss advanced care planning. Our goal initially was to screen patients for cognitive disorders after an initial visit and at least annually.

This CCC clinic led very naturally into a nice way to incorporate The Parkinson's Foundation Palliative Care initiative. We have adjusted our CCC template to include screening questions for care partner needs, spiritual concerns, and more systematically including advanced care planning discussions in addition to cognitive testing. Our goal is to screen all patients through this clinic, even those patients who are earlier in the disease course and would not typically be thought of as patients requiring palliative support. However, we hope this will allow us to address palliative needs throughout the patient's PD journey. We have been so pleasantly surprised by the way patients view this experience, which is often described as feeling that they are receiving more comprehensive care outside of the routine movement disorders clinic visit.

Our setback has been losing our wonderful social worker who was often involved in many aspects of the clinic, but we are hoping to fill her shoes soon. Our hope is that as our outpatient palliative care team expands, we will be able to incorporate them into our CCC clinic too. And that as our satellite clinics expand, we will be able to add a CCC structure to many sites around the DC area.

We thank you for the opportunity to collaborate and look forward to sharing more ideas together.



## **Center Spotlight: Palliative Care COE Implementation**

### **Building Relations with Local Hospice Organizations and Streamlining Referrals**

Jenna Iseringhausen, BSN, RN, Palliative Care Champion, The NYU Langone Marlene and Paolo Fresco Institute for Parkinson's and Movement Disorders

1. How did you build relationships with local hospice organizations? Any advice for centers who might want to build relations with hospice or find local organizations?

Most of the hospice organizations we refer to we found either through providers' positive experiences, or through previous care partner feedback. The best way to know how a home hospice service operates within the home is to ask the care partner. Throughout the start and to the end of the hospice process we ask for feedback from the patient and family. Building a relationship with the care partner over time allows for further support of that patient and their family, but also for future patients and their care partners within the center. We also do trainings and outreach to various home health aide and hospice agencies on Parkinson's disease and other movement disorders. This has allowed us to build resources within the community of PD and movement disorder trained home aids and nurses.

2. What does your referral process look like for hospice?

Over time, the process of referring to hospice transitioned to involve a collection of team members including the attending movement disorder provider, palliative care provider, social worker, and nurse on the team. The first point of contact tends to be the movement disorder provider. There is the option of referring directly to the nurse and social work team to initiate the hospice referral, or they can refer to the palliative care provider for a hospice discussion meeting.

If patients or family members are interested in learning more about hospice and the benefits, we arrange a one-on-one phone meeting between the patient, family member, and a nurse on the team. Once they have discussed with the RN or met with the palliative care provider, an order is placed for home hospice (including the hospice warranted diagnosis), and the note is written in the chart to document the specific triggers met for a hospice consult. Some of the triggers include frequent infections, hospitalizations, weight loss, wounds, abnormal lab results, frequent daytime sleepiness and fatigue. Each hospice company has a different process of referring. Following the specific protocol of that company, the hospice information is sent over. A follow up call from the RN or social worker is made to the hospice company to confirm receipt, and the patient and family are updated on the status including the direct contact information for the hospice company.

3. Any advice you would share for centers who want to implement something similar?

Take time to listen to the care partners within the center, build your resources slowly, train your team on the process of how to refer, and educate your patients and family members on hospice care. If there are not home agencies in your community who have knowledge of PD or movement disorders, take time for your team to do virtual in-services with their HHA, social workers, and nurses. This will allow for your team to work together in finding the right hospice services for your patient population, and to make the process as seamless as possible during this already challenging time for the patient and family.

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### **Question for the Palliative Care Coaches:**

**Question:** I referred a patient that I felt had early PD, mild symptoms with tremors, motor fluctuations and orthostatic hypotension. We discussed early memory changes, and I suggested palliative care given she expressed some worry for the future, to discuss advanced care planning.

The palliative care provider messaged me the following:

"Not sure there is much I have to offer her at this time as her most bothersome issue is tremor. She did make herself DNR/DNI but does not have strong wishes one way or the other regarding feeding tubes/artificial nutrition at this time."

I often run into this with other providers – I refer to speech therapy or PT and the provider will do an evaluation and "dc from treatment as no need". I suspect I am not making the referral reason clear enough, and perhaps that is because the extra time it takes for me to spell out the psychosocial details of the situation – but in this case the patient comes from a background of alcoholism in the family of origin, is a retired teacher, widowed after divorce from partner who was an alcoholic, lives alone and does a lot of exercise – used to do more like pool and ping pong but stopped as it's not fun anymore. I was hoping to get them some additional support and to explore issues of the existential distress they feel from their symptoms, etc. I do my best to provide support, but at times feel like I can't be all things to all people.



## **Response to the Question:**

By Christina Vaughan, MD, MHS, Palliative Care Coach, University of Colorado

**Response:** It is indeed very frustrating when a consultant claims they “don’t have much to offer.” Since Palliative medicine grew out of the world of Oncology, there is still much to do to strengthen relationships between neurology groups and palliative care teams. Oftentimes the palliative involvement with an oncology patient is focused on prognosis based on staging, treatment options, side effects from treatment, and the possible pivot to what life will look like when there are no more treatment options or trials to consider. In our patient population with PD, there is no similar scaffolding in the approach – we don’t have a meaningful staging system or tests to quantify progression, disease-modifying therapies, or a transition from treatment to none. The differences in our patient population may make the palliative care provider feel less useful as they are without the familiar frameworks of other disease states. This underscores the importance of this Parkinson’s Foundation initiative to encourage us all to strengthen the relationship between neurology and palliative care teams, to educate our palliative colleagues about disease states (invite them to lectures/programming) and remind them that while there are many differences between those living with cancer and those with parkinsonism, the palliative care approach applies to all.

In a typical palliative care consult the foundation for the encounter usually centers around a goals of care conversation. This is an exploration to elicit values, including questions such as “what was life like before the PD? What is a typical day like for you? How has your illness affected this? What are your hopes/worries? What matters most now?” Part of the role of the palliative care provider/team is to match up the patient’s values to medical care and medical decisions. For our patients with PD it is also helpful to discuss possible what-if’s of the future such as: “what functions are so important to you that you cannot imagine living without them? If you need more assistance with activities of daily living what kind of care would be acceptable to you?” Palliative care providers also commonly make medical recommendations based on the patient’s values (for example: “given that you most value your cognition and given the risks of prolonged anesthesia in people with advanced PD, I would not recommend that elective orthopedic surgery”).

The result of this palliative consult was truly disappointing, and it seems like an opportunity was missed to explore goals of care, make a medical recommendation about artificial nutrition (based on goals/values), and elucidate the psychological details.

Possible ways to mitigate this in the future could include:

- Invite the palliative team to PD-specific programming and ask them to speak at a PD support group (taking questions from patients/families can be major learning opportunity to highlight what matters most to them)
- Consider creating a checklist for palliative consult referral which could include:
  - Your estimate at prognosis using the surprise question: I would not be surprised if this patient died within (...the next year, 2 years, 5 years)
  - Then highlight which of the following is true:
    - Has quality of life significantly declined in the past 6 months-year for the patient and/or caregiver?
    - Does the patient have motor or non-motor sx that are refractory to treatment?
    - Is the caregiver struggling with feeling overwhelmed with their role, with feelings of difficult emotions (such as guilt, grief, anger), or having an increasingly strained relationship with the patient?
    - Does the patient and/or caregiver have significant worries about the future (such as loss of hope or of demoralization)?
    - Does the patient and/or caregiver have significant worries about the future (such as related to prognosis, what to expect as the PD worsens, future medical decision-making, transitions in care, how to clarify advance care plans)?

Thank you for seeking out your palliative colleagues to share in care with our patients and families living with PD.