



Parkinson's Foundation Palliative Care Newsletter

January 2022





Palliative Care Project Updates

1. Registration Information for the Palliative Care PD Health @ Home Series

- Our 2023 palliative care educational series for people with Parkinson's and their families launched on January 11th with an introduction on primary and specialist palliative care from Dr. Benzi Kluger. If you missed the live introduction, you can watch it and access additional resources by [clicking here](#).

This series will be airing throughout 2023 via the Parkinson's Foundation PD Health @ Home. Using this [link](#), people with Parkinson's and their families can register for entire series. The next palliative care episode will be on Wednesday, February 8th from 1:00-2:00 pm ET.

2. Access to "Team-Based Palliative Care Essentials" Course in New Learning Management System

- An email was sent out letting you all know that access to the palliative care education course titled "Team-based Palliative Care Essentials for Parkinson's" has been restored in our new learning management system - The Learning Lab. As you know, this course covers the core components of palliative care and how to integrate PC into existing frameworks of care. The course is accredited for physicians, physician assistants, nurses, and social workers (11.00 CME/CE). You can register and access the course [here](#). Please note that the palliative care project team will no longer be tracking completion by center and no action is required at this time. Importantly, the course is now **only** accessible in our online Learning Lab using the link above. The contents of the course are no longer accessible in the University of Rochester Box folders. Please send your team members the new link to access the course. The course will now live indefinitely in the Parkinson's Foundation Learning Lab, and you can register for the course to continue accessing the content.

Palliative Care Resources

- **Curriculum Innovations: Implementing a Neuropalliative Care Curriculum for Neurology Residents.**

This article describes a novel, multitiered curriculum in neuropalliative care communication for Neurology residents, including the evaluation of its feasibility and outcomes. Access the full article [here](#).

- **2022 International Neuropalliative Care Society (INPCS) Conference**

Registration for the conference has re-opened for on-demand access to conference content. With the coupon code DEMAND22, people who register now will receive 25% of the regular rates. You can reregister [here](#).

- **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. Access the course [here](#).

- **Optimizing Hospital Care for People with Parkinson's**

With support from CVS Health Foundation, this course is intended for hospital staff to learn how to better care for people with Parkinson's during planned and unplanned hospital stays. Free Continuing Credits (CEs) are available. You can register for the course [here](#).



Triggers for Referring to Hospice and Specialist Palliative Care

By Dr. Benzi Kluger, MD

The pillar of referring appropriate patients for specialist palliative care or hospice in a timely fashion seems different at first glance from the other pillars in that it appears to apply only to a limited number of Parkinson's patients. However, we would argue that to be systematic and proactive, this is an issue that should be considered for all patients. That being said, in many patients you can quickly screen them out for these services if they are overall doing well.

When screening for hospice, it is important to recognize that PD is the 14th leading cause of death in the US and is projected to be an increasing contributor to mortality in the future.^{1,2} Excess mortality in people with PD (PWP) tends to be related to aspiration pneumonia, other infections, and complications of falls.³ While PWP are currently more likely to die in a hospital or institution than at home, these statistics can be changed by proactive conversations, including advance care planning.⁴ By identifying PWP at increased risk for death earlier and having conversations about goals of care, including hospice, providers can give families greater security and control around end-of-life and avoid adverse outcomes, including hospital deaths, transfers to subacute nursing facilities, and invasive procedures near end-of-life, both of which can increase suffering for patients and family.⁵

Key red flags that may indicate a PWP is nearing end-of-life include the following:^{3,6}

- Recurrent hospitalizations for falls or infections or single hospitalization with substantial drop in function
- Weight loss
- Decreased appetite
- Dysphagia for thin liquids or secretions
- Accelerating loss of function including gait and activities of daily living
- Worsening dementia including withdrawal from activities and increased sleep

One can also use “the surprise question” (Would I be surprised if this patient died in the next 6-12 months?) as a means of screening.⁷ It should be noted that the goal of screening is to identify people early who may benefit from additional conversations or care and that the surprise question in particular is sensitive but not specific.

Regarding conversations about hospice, we recommend:

1. Start by clarifying goals of care. If someone wants to avoid hospitals and prioritizes comfort and time with family, hospice (or home palliative care if they don't meet prognostic criteria) may be appropriate. If they would still want to go to the hospital, hospice is not appropriate regardless of prognosis.
2. Next discuss services provided by hospice which include an alternative to calling 911; home medical care including nurse, APP, social work, and chaplain; medications and medical equipment; and (often) very limited nonmedical aid services.
3. Last clarify and discuss prognosis. You can acknowledge uncertainty when appropriate and note that for hospice one needs to be at risk for dying within 6 months, but people can get hospice for longer or even graduate from hospice if they do very well.

For screening for specialist palliative care, we anticipate that this will happen in the course of screening for the other 4 pillars and considering these additional questions: Would this patient or caregiver benefit from an extra layer of support? Depending on resources at your COE this could include extra help for complex goals of care discussions, psychosocial support, or challenging medical symptoms (e.g. pain). There are also more formal needs assessment tools that you could consider incorporating.^{8,9} When referring to palliative care consider using the phrase “would you like an extra layer of support”, referencing specific services (e.g. help with pain management), and using the name of the service (e.g. supportive care, next step clinic) as studies have shown that how people are referred to palliative care greatly influences whether they will complete the referral.¹⁰

References can be found [here](#). Passcode: aqN7Mo7e



Advance Care Planning (ACP) Case Studies

Read examples below on addressing ACP with PD patients. Answers to questions provided by Tom Carroll, M.D., Ph.D.

Case 1: Nancy is a 75-year-old woman with Parkinson's disease (onset in 2015) with cognitive impairment, currently residing in a SNF. She does not walk, communicates with a letter board, has no vocalizations, and requires assistance with eating. She's had one ED admission in the past year for facial cellulitis, and one hospital admission in the past two-years for NSTEMI, CAD, and a-flutter with RVR. For ACP, she has no MOLST on file, but the family reports she has full code status at her SNF. She has discussed her wishes in the past with her healthcare proxy; she's expressed that she would like chest compressions but not intubation.

Question 1: Is it even legally possible to have a MOLST that's "Attempt CPR" on page 1 but "DNI" on page 2?

Response: Legal? Yes. Medically appropriate? Essentially never. My view is that cardiopulmonary necessitation is a procedure like any other. It has risks and benefits, and it needs to be performed appropriately. Anyone who needs chest compressions also needs intubation, at least for airway protection. Related, while "CPR" is often used as synonymous with "chest compressions," I think we should make it clear that "cardiopulmonary resuscitation" includes both chest compressions and endotracheal intubation. We can also be explicit to patients that if "CPR" is successful, intubation may last only minutes if the patient wakes up immediately. The fact this is uncommon is due to the fact that CPR is much less effective than we wish and how media (TV, movies, etc.) generally depicts.

Question 2: I expect for DNR they may specify whether or not they'd like intubation, but if they specify "Attempt CPR" then how do we fill out the "Instructions for Intubation and Mechanical Ventilation" on Page 2? Can it be either a "trial period" or "intubation and long-term ventilation if needed", or must it be the latter?

Response: "Trial period" can be appropriate whether "DNR" or "Full Code"/" Attempt CPR" is selected. The reason for this is that chest compressions are only appropriate when there is no pulse while intubation can be indicated regardless of pulse status. Intubation/Ventilation can be discontinued (i.e., extubation) whenever continuing it longer achieving the patient's goals.

Question 3: Can you give an example of how you would approach the conversation to address this?

Response: "CPR is a procedure like any other, with risks and benefits...and those benefits depend on us having all of the necessary options available. If someone were to be "attempt CPR but DNI", I would worry that person would be exposed to the risks without the full benefits."

Case 2: Mary is a 73-year-old with advancing Parkinson's Disease (onset was 11 years ago). She has CAD, paroxysmal a-fib on warfarin, ischemic cardiomyopathy, chronic combined systolic and diastolic congestive heart failure. She had a pacer/Automatic Implantable Cardioverter Defibrillator (AICD) placed 2 years ago. She had a fall earlier this year (2022) and suffered a mild TBI with SAH. Subsequent CT showed no evidence of new bleeding. She's now back on warfarin for a-fib. She uses a rollator walker regularly but continues to fall once or twice a month because of freezing, tripping, and imbalance.

During a recent MOLST discussion, she indicated right away that she wants no extraordinary measures, and a family member said, "What about your kids and the grandkids?". I tried to open the discussion about CPR and the family pointed out that she has an AICD. I was not sure how that would affect these conversations and choices.

Response: To some extent, an AICD provides a "nice" (if you will) opportunity for "shocks only without chest compressions." Some patients choose to leave the AICD on while being DNR (with DNI or with trial of intubation). This allows for the "easily" fixed electrical problems (e.g., VT) to be corrected via AICD while avoiding the higher risk/lower benefit of attempted resuscitation for causes of pulselessness that are not easily fixable with shocks.