



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

**November 2022**





## **Palliative Care Project Updates**

**1. Palliative Care Education Course:** We are pleased to provide you and your team access to the online education course, “Team-based Palliative Care Essentials for Parkinson’s Disease.” This [link](#) (full link provided below) provides access to the course content in an online file sharing system (Box). No sign in or account is required. Videos cannot be downloaded but can be viewed within the folder.

- a. The final completion deadline to receive the second installment of project funding from the Parkinson’s Foundation is **December 31<sup>st</sup>, 2022**. To receive this additional funding, 50% of providers and 100% of Medical Directors and PC Champions must complete the entire course, and 75% of all other COE staff must complete Chapter 1.
- b. All course participants **must complete the survey** in the folder titled, “Required Course Completion Survey” in Box. This allows the project team to track center progress and ensures the required content has been viewed.
- c. Please note that access to the course content through this link is for project purposes only and by viewing in this manner you will not be eligible to receive any continuing education credit (CME/CE).
- d. Those who started watching the course in the old platform can pick up where they left off using the Box videos. They will need to confirm all necessary content was viewed for their role on the survey.
- e. The above information was also sent out to all PC Champions, Medical Directors, and Coordinators. Please email [mdini@parkinson.org](mailto:mdini@parkinson.org) if you have any questions or concerns.
- f. **Full link to access video course content in Box:**
  1. <https://rochester.app.box.com/s/85ql4cnji2thkt9dunpgmp5mnfmg6xss>

## **Palliative Care Resource**

- **Palliative care of End Stage Parkinsonism: An Overview Including the Five Pillars Framework**

The focus of this article is on end-stage parkinsonism. In addition to motor symptoms of bradykinesia, rigidity, and imbalance, patients with advanced PD increasingly experience difficult to control secondary symptoms such as chronic pain, mood disorders, dysphagia, and cognitive changes. Often these symptoms are a source of considerable distress for patients and their families. Access the article [here](#).

- **Caregiver Month 2022**

Every November, the Parkinson’s Foundation joins with organizations across the country to honor care partners for National Family Caregivers Month. This year, we aim to empower care partners by providing resources that will help them and their loved ones with Parkinson’s disease (PD) live better lives. We will send out a steady cadence of helpful resources so care partners can find exactly what they need, when they need it. The guide [here](#) provides simple instructions and tools to help you activate your community to support the campaign and how you can participate.



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

### **Simon's Simple Symptom Survey**

David K. Simon, MD, PhD, Director, Parkinson's Disease & Movement Disorders Center,  
Beth Israel Deaconess Medical Center

Parkinson's disease (PD) is highly variable between patients and can include a wide range of motor and non-motor symptoms. It can be difficult if not impossible to cover all of the potentially important issues during a typical follow-up visit. To facilitate our ability to screen across a wide range of potential symptoms and to allow us to focus our time during visits on the most important issues, some of the movement disorders doctors at our center are utilizing a 2-page (one page, both sides) screening questionnaire. The single most important question may be the first one, an open-response question asking them to, "Please indicate your main concern that you would like to discuss with your Neurologist today". The questionnaire then screens for 14 different non-motor symptoms as well as 11 different motor symptoms. These questions are in a table form so that patients can answer quickly by simply checking a box for each symptom indicating, none, mild, moderate, or severe. These are supplemented by a few additional questions, such as how many falls have occurred in the past week, month, and 6 months. Another question asks about formal exercise and how many days per week. We also ask if they are driving, and if so are there any safety concerns. And after completing the Parkinson's Foundation's palliative care training, we have added questions about care partner stress, and about HCP and MOLST forms. There may not be sufficient time to address all issues raised in the questionnaire during a single visit, but this screening tool helps to focus on the most important problems, which we may address through referrals to other subspecialists.

Patients are handed this form by the front desk staff when they check in for appointments. Usually this works, but as a back-up in case the front desk staff misses this, our medical assistants (who check vitals) also will ask if they received the form and will give it to them if not. Not every patient completes the form. For example, some may arrive late for their appointment with no time to complete it before being seen. But the majority of patients do complete it, and it takes only about 5 minutes. This completed form is then handed to the neurologist at the start of the visit. Initially it was difficult to get the front desk staff to hand it out consistently as they are quite busy and the staff varies from day to day. But a strategy of periodic reminders has helped, as well as going out of our way to thank them for handing it out when they did, and to let them know how very helpful that was. Also, the medical assistants (who take vitals after the patients check in) ask if they have received the questionnaire and can hand it out if needed, thus serving as a back-up. This questionnaire has been enormously helpful by making it possible to screen for a wide range of symptoms while also focusing on the more severe symptoms and on those that matter most to the patient. It has been a challenge to balance the goal of being comprehensive with the need to keep the form brief. An image of the completed forms are scanned into the patients' electronic records. Ultimately, we hope to have this process digitized so it can be completed either online before the visits or on a tablet in the waiting room.

You can access Simon's Simple Symptom Survey form in the Egnyte resource folder [here](#).



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## Cost and Return on Investment of a Team-Based Palliative Care Program for Parkinson Disease

Dr. Brett McQueen, a health economist from the University of Colorado Anschutz Medical Campus, along with Dr. Benzi Kluger and colleagues, looked at implementation cost and return on investment for implementing palliative care at the University of Colorado. Their findings are detailed in a recently published article. Read the brief description of the research study below by Dr. McQueen and access the article using the link.

Implementation of team-based palliative care in neurology settings may improve symptom control, quality of life, and reduce acute care admissions. The benefits of team-based PC for patients with Parkinson's disease (PD) has been established through rigorous evidence standards including randomized controlled trials. But questions remain on the sustainability of this model of care. In this study, we applied a unique costing approach combined with reimbursements to calculate total costs and return on investment for two outpatient clinics at the University of Colorado Hospital (UCH): neurology PC and movement disorders. We found that total potential reimbursement exceeded the personnel and other costs to implement and continue this model of care. Our results suggest both neurology PC and movement disorders clinics provided increased revenue to the health system. Opportunities to improve sustainability include efficient allocation of personnel to new and established visits, expanding telemedicine, and other cost offsets to complex patients not established in this analysis. There may be greater returns in health systems that benefit from cost savings such as accountable care organizations.

Access the article [here](#).

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](mailto:jnusrat@parkinson.org) to be answered in a future edition.

## An Opportunity to Learn about Spiritual Care!

The Palliative Care Research Cooperative Group is offering a webinar on spiritual care for people with serious illness based on the recommendations of the Systematic Review of "[Spirituality in Serious Illness & Health](#)". Details are provided below along with the link for registration.

**Title:** Making Spiritual Care a Routine Part of Care for People with Serious Illness: Recommendations from a JAMA Systematic Review

**Speakers:** **George Fitchett, Dmin, PhD**, Professor and Director of Research, Department of Religion, Health & Human Values, Rush University Medical Center, and Director, Transforming Chaplaincy

**Jean Kutner, MD, MSPH**, Chief Medical Officer, University of Colorado Hospital, Professor of Medicine and Associate Dean for Clinical Affairs, University of Colorado School of Medicine

**Alexia Torke, MD, MS**, Professor of Medicine, Indiana University School of Medicine, Chief, Section of Palliative Medicine, Indiana University School of Medicine and Director, Evans Center for the Integration of Spiritual and Religious Values in Healthcare.

**Shelley Varner Perez, MDiv, MPH**, Senior Program Manager for Spiritual Care Research, Indiana University Health

**Date:** December 5, 2022 3:00pm – 4:00pm Eastern Time (EST)

**Registration:** [https://partners.zoom.us/webinar/register/WN\\_LL4K-S5RQxWr\\_7EgD67INA](https://partners.zoom.us/webinar/register/WN_LL4K-S5RQxWr_7EgD67INA)

**REGISTRATION IS REQUIRED.**